Optimising healthcare for stroke survivors - a study of health professional perspectives on minimising treatment burden and maximising patient capacity

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Optimising healthcare for stroke survivors - a study of health professional perspectives on minimising treatment burden and maximising patient capacity

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Abstract

Objectives: Treatment burden is the healthcare workload experienced by individuals with long-term conditions and the impact on well-being. Excessive treatment burden can negatively affect quality-of-life and adherence to treatments. Patient capacity is the ability of an individual to manage their life and health problems and is dependent on a variety of physical, psychological and social factors. Previous work has suggested that stroke survivors experience considerable treatment burden and limitations on their capacity to manage their health. We aimed to examine the potential barriers and enablers to minimising treatment burden and maximising patient capacity faced by health professionals and managers providing care to those affected by stroke.

Setting: Primary and secondary care stroke services in a single health board area in Scotland.

Participants: Face-to-face qualitative interviews with 21 participants including stroke consultants, nurses, physiotherapists, occupational therapists, speech and language therapists, psychologists, general practitioners and health-service managers.

Outcome measures: Data were analysed using thematic analysis to ascertain any factors that influence the provision of low burden healthcare.

Results: Five key factors were identified that impact health professionals' ability to influence treatment burden and patient capacity: 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.

Conclusions: Our findings have important implications for the design and implementation of stroke care pathways, emphasising the importance of removing barriers to health professional provision of person-centred care. This work can inform the design of interventions aimed at nurturing autonomous working by health professionals, improving communication and care co-ordination or ensuring availability of a named person throughout the patient journey.

Keywords: Stroke, Treatment burden, Patient capacity, Healthcare perspective, Qualitative

Strengths and limitations of this study

Rigorous thematic analysis of interviews with twenty-one healthcare professionals and managers across the patient journey until data saturation reached.

Double coding of a subset of interviews and coding clinics enhanced reliability.

Due to the nature of qualitative research, findings should be considered as explorative and not definitive.

Findings can inform the development of interventions aimed at minimising treatment burden or maximising capacity such as improving communication and care co-ordination or ensuring availability of a named person throughout the patient journey.

Introduction

There is growing interest in exploring and measuring the self-management workload experienced by people living with long-term conditions. The term ‘treatment burden’ defines the workload of healthcare and its effects on a person’s well-being[1-3]. Clinical guideline bodies have emphasised the importance of treatment burden in recently published guidelines[4]. Excessive treatment burden is likely to negatively affect quality of life and adherence to treatments[5 6]. Non-adherence may arise if workload outweighs a person and their wider support network’s ability to manage their health, defined as patient capacity. Patient capacity is dependent on a variety of personal, physical, psychological, environmental and social factors such as frailty, health literacy, socioeconomic status, location, social support and cognitive functioning[2 7]. The design and implementation of clinical guidelines and the configuration of health services are thought to influence treatment burden and capacity to self-manage[2 7 8]. For example, over investigation, poor co-ordination between specialties or healthcare that is difficult to access may cause difficulties for service users and lead to them feeling overburdened by self-management demands.

Stroke is a common long-term condition in the primary care population[9]. Stroke survivors are at risk of high levels of treatment burden due to the intensity and longevity of treatments plus stroke can influence patient capacity, for example, through effects on physical ability, cognition and mood[8 10 11]. Additionally, stroke survivors often experience multimorbidity (two or more long standing health conditions) and so have additional treatment work related to additional long-term conditions[12]. Stroke survivors describe various types of treatment-related work including researching and understanding treatments, setting goals, interacting and negotiating with health professionals, engaging friends and family to help with organisational tasks, taking medications, attending appointments, making lifestyle changes and monitoring progress in recovery[8]. They report that treatment burden arises due to either a high volume of work e.g. a high number of tablets, or because of deficiencies in the way that care is delivered e.g. an unnecessarily complicated medication regime. Stroke survivors describe their transition into the community and subsequent longer-term care as particularly problematic, and this is an aspect of care that governing bodies have identified as requiring improvement[8 10].

Our previous research elicited the experience of treatment burden from the stroke survivor's perspective[8 10]. To inform the development of interventions aimed at minimising treatment burden and maximising patient capacity, it is important to develop an understanding of the potential barriers and enablers to provision of such healthcare. This has been an under-researched topic to date. Our aim was to examine the potential barriers and enablers to minimising treatment burden and maximising patient capacity as viewed by stroke care, managers and health professionals.

Methods

A stakeholder panel consisting of stroke survivors and health professionals was involved throughout the design, undertaking and reporting of this study. Ethical approval was granted by the University of Glasgow, College of Medical, Veterinary & Life Sciences (MVLS) Ethics Committee (Project no. 200170014).

Recruitment of participants

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. Potential participants were contacted via email and those who were interested were screened via telephone to ensure they met our inclusion criteria.

Data collection

Semi-structured face-to-face qualitative interviews lasting approximately 30-60 minutes were conducted by an academic GP (JK) between January and July 2018. The participant information sheet, interview schedule and consent forms are available in Appendices 1, 2 and 3. Interviews were digitally recorded and transcribed verbatim.

Data analysis

Data were analysed using thematic analysis; a method for searching, identifying and analysing patterns of meaning or themes, in a dataset[13 14]. Thematic analysis has six phases: familiarization with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report[13]. In our data analysis we followed a hybrid approach of qualitative methods of thematic analysis, drawing upon both inductive (i.e. data-driven) and deductive (i.e. based on pre-conceived ideas) approaches. This was an iterative and reflexive process with the data collection and analysis being conducted concurrently. Eighteen broad thematic categories (nodes) formed the code manual which can be found in Appendix 4. Furthermore, each node contained three sub-categories (sub-nodes):

facilitators; improvements; and barriers. These broad thematic categories were further clustered into overarching themes and were assigned succinct descriptions that captured the essence of each theme. 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. NVivo software was used to aid data analysis. A second researcher (DS) coded all transcripts, this researcher had considerable experience of qualitative data analysis but not of health-related research and so had little prior knowledge about the topic. To enhance reliability of coding, 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. Coding clinics were also held between DS, JK, KG and FM to discuss coding and to shape overarching themes. No further interviews were conducted once data saturation had been reached.

Patient and public involvement

The Research Advisory Group that guides this programme of research includes four stroke survivors or carers of stroke survivors. Their input has helped to guide the aims, objectives and methods of this study.

Results

Participant details are provided in Table 1. We identified five overarching themes that capture the factors described by health professionals and health service managers as influencing the minimisation of treatment burden and maximisation of patient capacity following a stroke. One key finding was that the factors identified were described as influential on the ability to provide person-centred care which in turn influenced treatment burden and patient capacity (see Figure 1). The five themes uncovered were: healthcare system structure; resources; knowledge and awareness; availability of social care; and patient complexity. Tables 2 and 3 detail the barriers and facilitators respectively to providing care that minimises burden and maximises capacity within each overarching theme. Below we describe and discuss pertinent factors that were commonly reported by participants.

Healthcare system structure

Participants reported that the structure of the healthcare system they were operating in was hugely influential on their ability to provide low-burden, personalised care. This included the systems and processes in place to allow communication and co-ordination between health professionals, and to encourage autonomous working with flexibility in care provision.

A key obstacle identified by most of our participants was the lack of standardised communication procedures between and within work settings (i.e. hospital and community settings; primary and secondary care; health and social services). There was a desire for more structured communication procedures, for example between health and social care:

> *As a consultant you are asking: has the referral been made, has it been received? Has someone been appointed, have we heard from them? […] We are having to just constantly seek where we are up to on that process so there is no online information about where any of that is. It's all communicated by telephone. It's all proactive social workers who may update the ward, otherwise the ward is chasing*

> *that information. It's quite labour intensive to see where we are up to with things. Participant 14*

Several interviewees reported that communication and coordination between health professionals can be particularly problematic in the discharge process:

> *It's sometimes quite difficult to track down social workers and to get the information that you need from social workers and perhaps to get access to them at a good time for patients as well. And I think a lot of discharges are delayed because of difficulties with that side of things. Participant 9*

Most participants highlighted the importance of a system that fosters good communication between health professionals and also collaborative working, for example regular face-to-face multidisciplinary meetings and case conferences in the hospital setting:

> *In the inpatient setting I think the multi-disciplinary model helps because you have then got not just a physician view of the world, you've got the nurses and the therapists talking about the person's other limitations and if you have got a really good named nurse that will often know the sort of psychological concerns the person has as well. So you will get a really, a much more complete picture. So I think that works well although I was going to say it's time consuming but it's probably only you know these meetings are maybe only a bit over an hour a week all told for the stroke unit so I think that's a big plus. Participant 11*

Participants also described working in an inflexible system where health professionals were discouraged to work autonomously due to rigid protocols and procedures. This prevented the provision of individualised care as they felt unable to tailor care to their patient's needs.

Resources

Resources in both the hospital and community were highlighted as important. A key resource issue in the secondary care setting was nursing staff shortages on the wards. This was raised by virtually all participants working in the hospital setting, irrespective of their profession:

> *The nursing staff are short staffed, they don't have two people that can walk round to the toilet so they use the machine called the steady to take them to the toilet which is a much easier, quicker way for them to do it but then that cuts back on that rehab potential so there is those kind of issues I would say but I think that harps back to probably the staffing issues overall. And having the time. I think the nurses don't have time to be rehab nurses. Participant 3*

Limited access to in-hospital investigations was highlighted, which was reported as delaying progress of recovery and prolonging hospital stays. A shortage of psychologists in the community was also reported by many and this was described as having a detrimental impact on stroke survivors' self-efficacy and ability to adjust to new disabilities or other difficulties. Despite shortages in the community, many participants praised the availability of stroke-dedicated psychology services in the hospital setting:

> *We have a strong and very healthy stroke psychology team in Glasgow and I think I'm really pleased with the extent to which that team works as part of the multi-disciplinary stroke service. I think it becomes a bit more fragmented when it goes in, when you come back into the community. I'm thinking about in an acute environment. From an acute perspective we have got a very good stroke/psychology team. Participant 19*

Knowledge and Awareness of both Patients and Professionals

Participants acknowledged that increasing stroke survivors' knowledge of the treatments and services available to them could lessen their treatment burden. They identified several factors that can hinder the successful transfer of information. One important obstacle was difficulty in providing person-centred information at the right time for the patient. For example, secondary care professionals described a lack of one on one time with patients and also having access to them during the acute phase of stroke when retaining information may be difficult:

> *It would be great if there was more of a person assigned to you and you saw them right through the journey or you had a contact point who you could regulate input information if you needed to. I don't know if it would be easy to work but that would probably be an ideal from a patients' point of view. Participant 1*

They reported that health professionals' knowledge was also important, for example it was felt by some that those working in social services and primary care may lack specialised knowledge about stroke recovery.

Stroke nurse, pharmacist and volunteer visits to stroke survivors on the ward and in the community were deemed to be important facilitators of increasing patients' knowledge and awareness of services:

> *We are fortunate here that we've got stroke nurse specialists who are sort of board employees and we've got two in 'x hospital' and one up at 'Y hospital' where our rehab unit is. All of the Greater Glasgow and Clyde hospitals have stroke nurse specialists and one of their specific roles is information provision to patients and their families. Participant 15*

The existence of a written information booklet that had been made available by the health board called the 'My Stroke booklet' was highlighted by many participants as a helpful source of information to distribute to patients. However, a few of the interviewees indicated a shortage of these booklets in their work settings.

Availability of social care

Inconsistent or insufficient provision of social services in the community was mentioned by many of the health professionals interviewed:

> *Depending on the area that the person lives in, depends how quickly homecare get puts into place. So 'area X' is good, 'area B' is not. So we have to be very proactive about saying to 'area B' come on, come on these people need this and they need it now but it might not go onto place quickly. Participant 13*

The important role of informal social networks such as friends and family were highlighted as very important following discharge into the community:

> *Social networks can have a very positive or a negative impact on patients. You know, if people are isolated then they might find it harder to be able to manage their long-term condition. But I think certainly a lot of the successes we see are with patients who have got more supportive networks. Participant 12*

Patient Complexity

Many interviewees highlighted that it could be challenging to provide suitable, individualised care to those with complex post-stroke cognitive, physical or psychological difficulties:

> *There is always a challenge getting the right information to patients at the right time and I think with stroke patients that's particularly challenging because of the emotional issues immediately after a stroke and the cognitive issues and that the language issues obviously some people can't read information and taking on new information is very difficult. You are talking about patients with language problems, cognitive issues, their life turned upside down so they've got all sorts of psychological problems. Participant 9*

Patient self-efficacy was commonly reported as influential on how care was provided, for example, shared decision making was easier in a patient with confidence in achieving their goals. Multimorbidity and polypharmacy were another challenge cited by several participants due to the increased workload of healthcare experienced by patients with multimorbidity and the increased risk of treatment interactions.

For complex patients, ensuring a sense of continuity throughout the rehabilitation process was deemed to be important to minimise treatment burden. Hence, the majority highlighted the importance of a named stroke nurse, or other designated person, throughout the patient journey:

> *If [stroke survivors] even had somebody they could phone or somebody came out to their house after they were home and said you know, these are the things that might happen or [...] if you have got any concerns or problems give us a phone. I think there should be regular contact, not necessarily with the stroke nurses in the hospital but again through health centres or GP surgeries or whatever they should be, a stroke nurse or somebody similar who can get into the community and just, not necessarily know everything about it but be able to say this is the number you can call. Participant 4*

More experienced health professionals (i.e. 10+ years in job) noted that in recent years the role of the stroke nurse has been limited to the hospital setting, with rare visits in the community environment. This was felt to be an important resource issue that has negatively impacted on the provision of care for complex patients.

Discussion

Summary of findings

This is the first study to explore health professional and healthcare managers perspectives on barriers and facilitators to providing healthcare that is minimally burdensome for stroke survivors whilst enabling their recovery. Five major factors were reported as being influential on providing low burden healthcare: healthcare system structure; resources; knowledge and awareness; availability of social care; and patient complexity. These factors were reported as influencing treatment burden and patient capacity through impacting health professionals' abilities to provide person-centred care. Many participants described working in an inflexible system where communication and co-ordination between specialities is substandard and key resources such as ward nursing staff and community psychologists are lacking. Educating patients about their treatments was felt to be very important, yet the interviewees often reported difficulties in obtaining the time and materials to adequately do this. Patient complexity was acknowledged as becoming increasingly common and having a major impact on the way health care is provided, for example it may be harder to minimise treatment burden and maximise patient capacity in a frail patient with multiple long-term conditions. Deficiencies in the availability of social care was reported as an important factor affecting patient capacity, particularly if the patient lacked an informal social network who could help them manage their health. All participants acknowledged the importance of providing healthcare that minimises treatment burden and maximises patient capacity, yet they often felt they were prevented from being able to do so by the health and social care system that they worked in. Findings suggest that changes at the macro level are needed to foster an environment that supports the provision of person-centred, low-burden care for stroke survivors. Commonly suggested improvements made by participants to overcome the barriers reported are presented in Table 4.

Strengths and limitations

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. One key strength was that data saturation was reached, another was the inclusion of health professionals across the stroke survivor journey, from acute through to primary care. Double coding of a subset of interviews enhanced coding reliability.

How does this compare to previous research?

Treatment burden is a relatively new concept in the medical literature that has been infrequently examined in stroke. While this is the first study to examine professional perspectives on barriers and facilitators to reducing treatment burden and maximising capacity in those with stroke there has been some published literature on this in relation to patient perspectives. We previously conducted a large systematic review of the qualitative literature [10] and conducted our own qualitative study [8]to examine the patient experience of treatment burden in stroke and the factors that influence patient capacity. The aspects of care that stroke survivors described as being influential on treatment burden and patient capacity were very similar to those reported here by health professionals: substandard information provision; poorly co-ordinated care, particularly during discharge from hospital into the community; a lack of continuity of care; long waiting times for investigations; and poor access to psychological services in the community. Both health professionals and stroke survivors emphasised the importance of person-centred care. Another recent systematic review examined stroke survivors' and their caregivers' experiences of community healthcare [15]. Although focussed on care in the community and not aimed at examining treatment burden, findings again resonated with professional perspectives in that stroke survivors reported continuity of care, access to psychological services, information provision, access to social care, communication between services and fluidity of care as influential on their experience of healthcare. A recent meta-review examined systematic reviews of qualitative studies that had examined the experience of self-management for stroke survivors[11]. Again, patients identified similar issues to those we have found with health professionals in this study, particularly relating to the varying needs across the patient journey and a requirement for better information provision, social care, patient -professional communication, and psychological support in the community. The similarities in findings between these previous studies of stroke survivors and our current study of health professionals strengthens the argument for system-level change in the way we provide healthcare that allows health professionals to deliver person-centred care.

What further research is needed?

Findings from this study of health professionals and our previous examination of the patient experience of treatment burden highlights the need to develop interventions aimed at minimising treatment burden and maximising capacity in those with stroke. The current study should inform the development of such complex interventions. Examples of potential interventions include: introduction of electronic systems to enable better communication between specialties; a named person throughout the patient journey (both in the hospital and the community); a routine review in primary care soon after discharge from hospital; or online access to a stroke community for peer support. To ascertain if such interventions are successful, it is important to be able to measure treatment burden in those with stroke, and therefore development of a patient-reported measure of treatment burden for this patient population is required. PRMs of treatment burden have recently been developed for use in other patient groups [16-18] and augmentation of these with validation in a stroke population may be suitable.

Conclusion

This study gives insight into the perspectives of healthcare managers and professionals regarding the barriers and facilitators to providing healthcare that minimises treatment burden and maximise patient capacity to manage health. Findings resonate greatly with our previous studies of the perspectives of stroke survivors[8 10]. A key finding was that the provision of person-centred care is fundamental. The findings should be used to inform the development of future complex interventions aimed at minimizing treatment burden for stroke survivors and maximising their capacity to manage health problems.

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Author contributions

KIG and FSM contributed to the design of the project. JK conducted the interviews. DS conducted data analysis and JK double coded a subset of the transcripts. KIG, FSM, DS and JK all took part in coding clinics. DS and JK wrote a first draft of the paper and all authors reviewed drafts and approved the final version.

Competing interests

KIG received funding from The Stroke Association to complete this work. FSM received payment for educational activities from Janssen outside the submitted work.

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Data sharing statement

Data are available upon request to the corresponding author. As data contain information which may lead to the identification of study participants, funding would be required to support anonymisation of the data.

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Table 1 Participants' profile

	Age			Gender		Years in job			Work environment		Profession							
	18-34	**35-50**	**51-69**	**M**	**F**	**1-5**	**5-10**	**10+**	**Hospital**	**Community**	**Stroke consultant**	**Physio**	**Stroke nurse**	**Health service manager**	**GP**	**SALT**	**Psychologist**	**OT**
Number of Participants	1	15	5	6	15	5	7	9	16	5	5	5	3	2	2	2	1	1

Table 2 Barriers to providing health-care that minimises treatment burden and maximises patient capacity

Theme	**Structure of Healthcare System**	**Resources**	**Availability of Social Care**	**Patient Complexity**	**Knowledge and Awareness of both Patients and Professionals**
Barriers	*Communication and co-ordination between health professionals:* disjointed electronic systems; lack of standardised communication procedures yet rules around using informal avenues; poor coordination during the discharge process; lack of a names nurse that links hospital and community care. *Lack of autonomy for healthcare professionals:* rigid protocols; feeling of disempowerment; inflexibility in support and follow up that can be offered; rigid post-discharge readmission procedures.	*Hospital* : ward nurses; stroke-specialist nurses; investigations; therapies; rehab equipment; beds on stroke wards; rehab spaces; patient stimulation e.g. activities on the ward; TIA clinic staff. *Community:* patient transport; rehab equipment; psychological support; facilities for physically disabled stroke survivors e.g. ramps on buses; CST staff especially psychologists and physios.	*Complicated financial support procedures:* particularly for those of pre-retirement age (65). *Inconsistent or insufficient social services* e.g. stroke clubs, home care, home adjustments. *Inadequate involvement of social networks* in the care of stroke survivors.	*Socio-economic vulnerabilities* e.g. poor housing conditions. *Lack of self-efficacy* e.g. lack of confidence in achieving goals. *Cognitive, physical, psychological and other post-stroke difficulties* e.g. poor mobility, low mood affecting progress. *Poor educational and IT literacy levels* e.g. can limit access to online resources. *Multimorbidity and polypharmacy* – higher risk of treatment burden with multiple long-term conditions.	*Lack of timely and personalised information* provision to stroke survivors. *Social care's lack of awareness around psychological difficulties* suffered after stroke. *Lack of GPs' specialisation* in post-stroke difficulties.

Table 3 Facilitators to providing health-care that minimises treatment burden and maximises patient capacity

Theme	**Structure of Healthcare System**	**Resources**	**Availability of Social Care**	**Patient Complexity**	**Knowledge and Awareness of both Patients and Professionals**
Facilitators	*Communication between health professionals:* electronic communication; pre-existing or personal contacts. *Collaborative working:* regular multidisciplinary meetings; interdisciplinary collaboration e.g. between different health professionals and services.	*Hospital:* stroke training for nurses; activities and facilities available on wards; stroke specific psychological support; opportunity for participation in clinical trials. *Community:* provision of home adaptations for physical disability; intensive and goal-driven therapy.	*Peer support* for stroke survivors and carers. *General vitality programmes* in the community. *Social network support* e.g. friends and family living locally.	*Screening for psychological and cognitive difficulties* at routine check ups. *Named keyworker* throughout the 'stroke journey'. *Patient self-efficacy*. *Shared decision-making* and visual aids that foster this. *Regular medication reviews*. *Dossette boxes*. *Consultants with geriatric backgrounds* - better able to deal with multimorbidity.	*Pharmacist visits* in the ward to provide info to stroke survivors about medications. *Written information*. *Stroke nurse* visits in the ward and community. *Chest, Heart and Stroke welfare officers*. *Online self-management tools*. *'In-house' primary and secondary care information services.* *Transparency in services available* in the community.

Table 4 Suggested improvements per theme

Theme	**Structure of Healthcare System**	**Resources and Provisions**	**Availability of Social Care**	**Patient Complexity**	**Knowledge and Awareness of both Patients and Professionals**
Suggested Improvements	Introduction of a named person to facilitate communication between services e.g. ‘discharge coordinator’. Autonomous working to enable person centred care. Improved communication between services and specialities e.g. ability to call a named person or meet face to face.	Investment in the provision of psychological support services in the community. Increased numbers of nursing staff in hospitals, particularly in stroke wards.	Enhancement of social network support, particularly for those with weak social networks e.g. prompt support group referral.	Routine patient follow-up reviews and medication reconciliation in the community.	Tailored information provision to stroke survivors in accessible language and format. Designated contact person throughout the 'stroke journey'.

Figure Legends

Figure 1 Areas in which treatment burden can be minimised and patient capacity can be maximised

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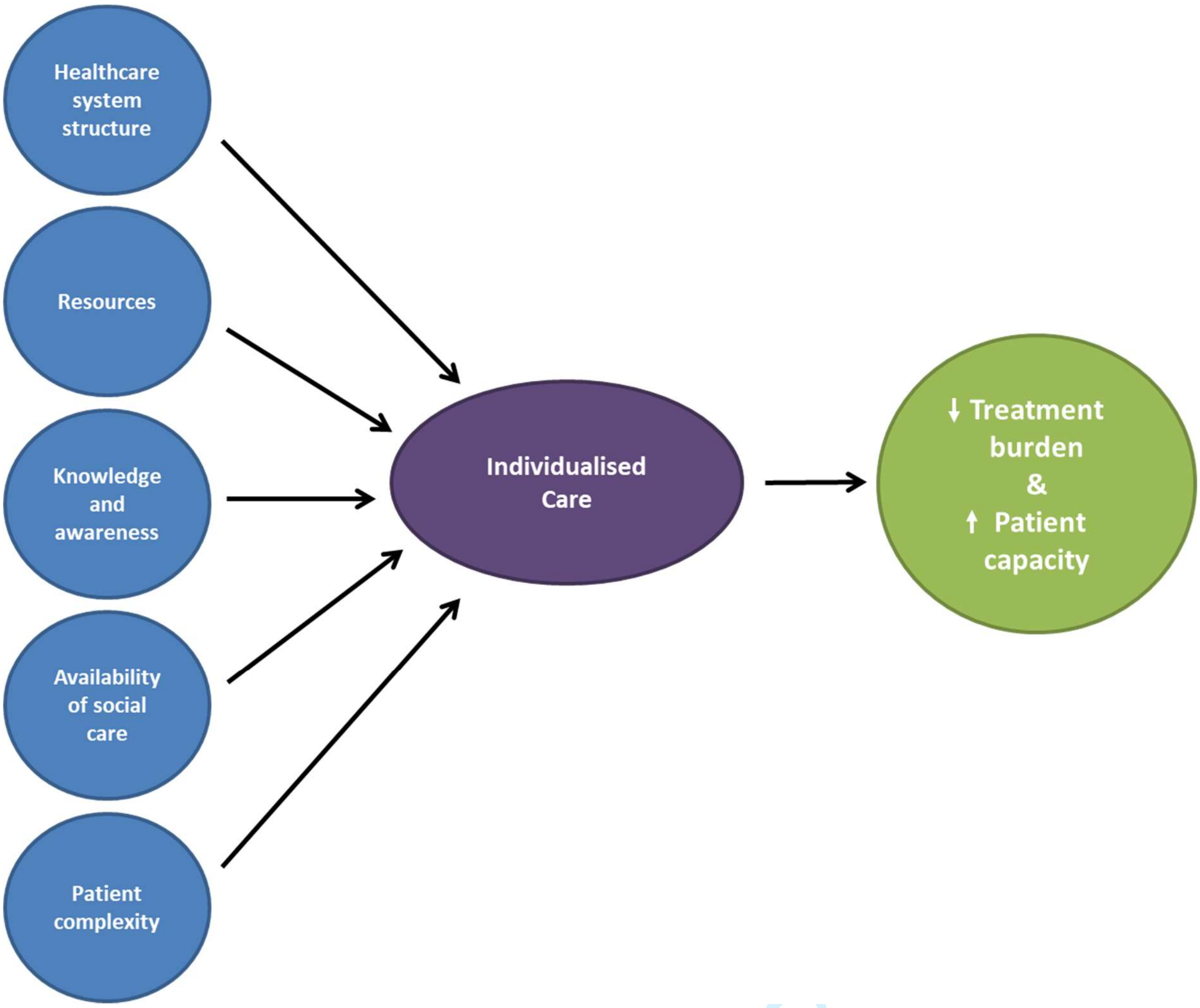

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PARTICIPANT INFORMATION SHEET

Study title

Optimising healthcare for stroke survivors - a study of health professional perspectives on minimising treatment burden and maximising patient capacity.

What is the purpose of the study?

Research has shown that people who have had a stroke can find it difficult to follow treatments recommended by their doctors, nurses and therapists. For example, medication regimes can be complicated, information on treatments lacking and communication between GPs and hospital doctors poor. This nine-month project is part of a wider programme of work aimed at developing interventions that can reduce the burden of treatment felt by stroke survivors and improve their abilities to self-manage health problems. In this project, we aim to understand from the perspective of healthcare professionals, service planners and policy makers why problems described by people with stroke may arise, and how we can develop new ways of providing healthcare for people with stroke.

Why have I been chosen?

You have been chosen as a potential participant because you either provide healthcare to stroke survivors or you are involved in the planning of this healthcare. We plan to interview approximately 20-25 people who provide stroke care or are involved in planning stroke services and policies.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form (you will also be given copy of the signed consent form). If you decide to take part, you are still free to withdraw at any time and without giving a reason.

What will happen to me if I take part?

If you choose to take part, you will be interviewed once in a location that is convenient to you, for example your place of work. The interview will last approximately one hour.

What are the possible disadvantages and risks of taking part?

You will be giving up your time to take part in this research project. Any travel expenses will be reimbursed. There is a small risk that you may find discussing certain experiences upsetting, for example a difficult clinical experience in the past or personal experience of stroke services. The person conducting the interview will direct you to your GP or local counselling services if this is required.

What are the possible benefits of taking part?

You will receive no direct benefit from taking part in this study. The information that is collected will help us better understand the factors that may prevent or enable the provision of stroke care that reduces the burden of treatment felt by stroke survivors and maximizes their capacity to manage their health. It will inform the development of future interventions for people with stroke.

Will my taking part in this study be kept confidential?

All information which is collected about you, or responses that you provide, during the course of the research will be kept strictly confidential. You will be identified by an ID number, and any information about you will have your name and address removed so that you cannot be recognized from it. Please note that assurances on confidentiality will be strictly adhered to unless evidence of serious harm, or risk of serious harm, is uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies.

What will happen to the results of the research study?

We aim to publish the results of this study in a peer-reviewed journal, and will present this work at national and international conferences. You will not be identified in any report, publication, or presentation. Articles published in peer reviewed journals are made available free of charge on the University of Glasgow website https://eprints.gla.ac.uk/

Who is organising and funding the research?

This project is being organised by the Institute of Health and Wellbeing at the University of Glasgow. The work is being funded by *(insert funder here)*.

Who has reviewed the study?

This project has been reviewed by the MVLS Ethics Committee at the University of Glasgow.

Contact for Further Information

Dr Katie Gallacher
Katie.gallacher@glasgow.ac.uk
0141 330 8323
General Practice and Primary Care
Institute of Health and Wellbeing
1 Horselethill Road
G12 9LX
University of Glasgow

What if I have a complaint about the study?

There is a standard complaints procedure which can be followed if you have any complaints related to this study. Please contact - Professor Kate O'Donnell, Department of General Practice and Primary Care, 1 Horselethill Road, University of Glasgow, G12 8RW, telephone no 0141 330 8329. This contact is independent to our study team.

Thank you for considering taking part in this study.

INTERVIEW GUIDE: Health professional perspectives on minimising treatment burden and maximising patient capacity

Background Information for the Interviewer

In situations where there is a lack of knowledge, questions will be posed in a manner which takes account of such a limitation.

The interview will be semi-structured in format, and thus the exact wording and prompts used may vary between participants to encourage them patient to share their views.

Introduction Procedure with Patients

1. Give complete name.
2. Identify self as a researcher from the Department of General Practice and Primary Care at the University of Glasgow.
3. Give short explanation of the purpose of the study:

'I would like you to help me understand the factors that influence how you plan or provide healthcare for stroke survivors. I am interested in particular about how we can provide healthcare that minimizes the burden on stroke survivors and maximizes their capacity to manage their own health. Please feel assured that no one will be able to identify you from what you say when talking to me and everything you tell me will be treated in the strictest confidence. As findings are recorded, please do not state the names of any patients or other identifiable information during the interview'

13/9/17 Version 2

If at any time you want to stop, or have a break, please feel free to let me know.

'I will be recording the interview, so I can remember all that you have said to me.'

PARTICIPANT PROFILE

Subject ID:

Age:

Gender: Male ( ) Female( )

Profession:

Stroke consultant	( )
Stroke doctor in training	( )
Stroke nurse	( )
Physiotherapist	( )
Occupational therapist	( )
SALT	( )
Psychologist	( )
Practice nurse	( )
GP	( )
Policy maker	( )
Health service manager	( )
Other	( ) Please state:

Do you work in the:

Hospital Setting	( )
Community	( )
GGC offices	( )
Government offices	( )
Other	( )

13/9/17 Version 2

How long have you worked in this job?

<1 year ( )

1-5 years ( )

5-10 years ( )

>10 years ( )

Practice nurse ( )

Date and Time of Interview:

The interviewer will therefore explore the following general areas in an open fashion:

Information provision

Do you feel that information provision is currently adequate for stroke survivors?

If not, how could it improve?

What facilitates and prevents good information provision?

Multimorbidity

Do you think that comorbidities are dealt with adequately by stroke services?

If not, how could this be improved?

What facilitates and prevents stroke services dealing with comorbidity?

Who should deal with comorbidity e.g. community stroke team / hospital doctors / primary care?

Care co-ordination

How well do hospital teams and community stroke teams communicate?

How well do primary and secondary care communicate?

How well do health and social services communicate?

What facilitates and prevents the above communication?

13/9/17 Version 2

Hospital stay

Do you feel the hospital stay could be improved for stroke survivors?

If so, how?

Do stroke survivors undergo enough rehabilitation when in hospital?

Is the nursing care adequate?

What factors would prevent and facilitate improvements to the hospital stay?

The discharge process

What are the pros and cons of the current discharge process that patients undergo?

How could it be improved?

What would facilitate or prevent such improvements?

Access to services in the community

Do you think that stroke survivors have adequate access to stroke services in the community?

If not then what services are difficult to access and why do you think that is?

What would improve and prevent better access to these services?

Medications

How could stroke survivors be helped to understand their medications better?

How could stroke survivors be helped to adhere to medications?

Are stroke survivors prescribed too many medications?

How often should these be reviewed and by whom?

Financial aid

Do you think that stroke survivors get adequate financial aid following their stroke?

If not, how could this be improved?

What factors facilitate and prevent this aid reaching stroke survivors?

Who should provide support with this process?

Shared decision making

Do you think that shared decision making is helpful to stroke survivors?

What do you think facilitates and prevents shared decision making?

Supporting the social network

Does an individual's social network (friends, family, neighbours) influence their ability to manage their health and follow treatments?

If so, how?

How can health and social services provide social support for stroke survivors and enahnce their social network?

What factors may prevent or enhance the provision of such support?

Self-efficacy

Do health services currently promote self-efficacy in stroke survivors?

How might they do this better?

What are the potential barriers and facilitators to this?

Physical disabilities

Do health services adequately support stroke survivors with physical disabilities in the community?

How might they do this better?

What are the potential barriers and facilitators to this?

Cognitive difficulties

Do health services adequately support stroke survivors with cognitive difficulties in the community?

How might they do this better?

What are the potential barriers and facilitators to this?

Psychological difficulties

Do health services adequately support stroke survivors with psychological difficulties (e.g. low mood , anxiety) in the community?

How might they do this better?

What are the potential barriers and facilitators to this?

At close of Interview

The interviewer will ask the participant if there are any issues they would like to mention which haven’t been covered.

And thank the participant, and reiterate that all they have discussed is confidential.

13/9/17 Version 2

University of Glasgow | College of Medical, Veterinary & Life Sciences

Centre Number:
Project Number: 301100
Subject Identification Number for this trial:

CONSENT FORM

Title of Project:
Optimising healthcare for stroke survivors - a study of health professional perspectives on minimising treatment burden and maximising patient capacity

Name of Researcher(s):
Dr Katie Gallacher
Prof Frances Mair

	Please initial box
I confirm that I have read and understand the information sheet dated __________ (version _____) for the above study and have had the opportunity to ask questions.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.	☐
I agree to take part in the above study.	☐

______________________________	____________	______________________
Name of subject	Date	Signature
______________________________	____________	______________________
Name of Person taking consent (if different from researcher)	Date	Signature
______________________________	____________	______________________
Researcher	Date	Signature

(1 copy for subject; 1 copy for researcher)

College of MVLS
Ethics Committee

Version 2 13/9/17

Initial broad thematic categories (nodes) that formed the code manual

1. Information provision to stroke survivors
2. Communication between Health & Social services
3. Support for psychological difficulties
4. Support for physical disabilities
5. Support for cognitive difficulties
6. Communication between Hospital & Community teams
7. Communication between Primary & Secondary care
8. Nursing Care
9. Dealing with co-morbidities
10. Social services support in the community
11. Medication Adherence
12. Medication Review
13. Financial Support
14. Discharge Process
15. Community Stroke Team Support (CST)
16. Hospital stay
17. Rehabilitation in the Hospital
18. Rehabilitation in the Community

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Title and abstract

	Page.
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	4
Purpose or research question - Purpose of the study and specific objectives or questions	5

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	4,6
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	7
Context - Setting/site and salient contextual factors; rationale**	5,6
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	5,6
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	5
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	6

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	6, appendices
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Table 1
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	6
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	6
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	7

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	7-14
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	7-14

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	14-17
Limitations - Trustworthiness and limitations of findings	15

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	18
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	18

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388

BMJ Open

What helps and hinders the provision of healthcare that minimises treatment burden and maximises patient capacity? A qualitative study of stroke health professional perspectives

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Primary Subject Heading:	Patient-centred medicine
Secondary Subject Heading:	Cardiovascular medicine, Health services research, Qualitative research, Rehabilitation medicine, Neurology
Keywords:	STROKE MEDICINE, treatment burden, healthcare perspective, QUALITATIVE RESEARCH, patient capacity, Organisation of health services < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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For peer review only

What helps and hinders the provision of healthcare that minimises treatment burden and maximises patient capacity? A qualitative study of stroke health professional perspectives

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Abstract

Objectives: Treatment burden is the healthcare workload experienced by individuals with long-term conditions and the impact on well-being. Excessive treatment burden can negatively affect quality-of-life and adherence to treatments. Patient capacity is the ability of an individual to manage their life and health problems and is dependent on a variety of physical, psychological and social factors. Previous work has suggested that stroke survivors experience considerable treatment burden and limitations on their capacity to manage their health. We aimed to examine the potential barriers and enablers to minimising treatment burden and maximising patient capacity faced by health professionals and managers providing care to those affected by stroke.

Setting: Primary and secondary care stroke services in a single health board area in Scotland.

Participants: Face-to-face qualitative interviews with 21 participants including stroke consultants, nurses, physiotherapists, occupational therapists, speech and language therapists, psychologists, general practitioners and health-service managers.

Outcome measures: Data were analysed using thematic analysis to ascertain any factors that influence the provision of low burden healthcare.

Results: 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.

Conclusions: Our findings have important implications for the design and implementation of stroke care pathways, emphasising the importance of removing barriers to health professional provision of person-centred care. This work can inform the design of interventions aimed at nurturing autonomous working by health professionals, improving communication and care co-ordination or ensuring availability of a named person throughout the patient journey.

Keywords: Stroke, Treatment burden, Patient capacity, Healthcare perspective, Qualitative

Strengths and limitations of this study

Interviews with twenty-one healthcare professionals and managers across the stroke patient journey.

Recruitment, data collection and analysis were conducted as an iterative process with arising themes prompting recruitment of certain types of health professional and interview questions.

Rigorous thematic analysis was conducted, drawing upon both inductive (i.e. data-driven) and deductive (i.e. based on pre-conceived ideas) approaches, until data saturation reached.Double coding of a subset of interviews and coding clinics enhanced reliability.

Due to the nature of qualitative research, findings should be considered as explorative and not definitive.

Introduction

There is growing interest in exploring and measuring the workload of health management experienced by people living with long-term conditions. The term ‘treatment burden’ defines the workload of healthcare and its effects on a person’s well-being[1-3]. Clinical guideline bodies have emphasised the importance of treatment burden in recently published guidelines[4]. Excessive treatment burden is likely to negatively affect quality of life and adherence to treatments[5 6]. Burden of Treatment Theory is a formal theory that models the relationship between patients, their social networks and healthcare services [2]. Non-adherence may arise if workload outweighs a person and their wider support network’s ability to manage their health, defined as patient capacity. Patient capacity is dependent on a variety of personal, physical, psychological, environmental and social factors such as frailty, health literacy, socioeconomic status, location, social support and cognitive functioning[2 7]. The design and implementation of clinical guidelines and the configuration of health services are thought to influence treatment burden and capacity to manage health issues [2 7 8]. For example, over investigation, poor co-ordination between specialties or healthcare that is difficult to access may cause difficulties for service users and lead to them feeling overburdened by health management demands.

Stroke is a common long-term condition in the primary care population[9]. Stroke survivors are at risk of high levels of treatment burden due to the intensity and longevity of treatments plus stroke can influence patient capacity, for example, through effects on physical ability, cognition and mood[8 10 11]. Additionally, stroke survivors often experience multimorbidity (two or more long standing health conditions) and so have additional treatment work related to additional long-term conditions[12]. Stroke survivors describe various types of treatment-related work including researching and understanding treatments, setting goals, interacting and negotiating with health professionals, engaging friends and family to help with organisational tasks, taking medications, attending appointments, making lifestyle changes and monitoring progress in recovery[8]. They report that treatment burden arises due to either a high volume of work e.g. a high number of tablets, or because of deficiencies in the way that care is delivered e.g. an unnecessarily complicated medication regime. Stroke survivors describe their transition into the community and subsequent longer-term care as particularly problematic, and this is an aspect of care that governing bodies have identified as requiring improvement[8 10].

Our previous research elicited the experience of treatment burden from the stroke survivor's perspective[8 10]. To inform the development of interventions aimed at minimising treatment burden and maximising patient capacity, it is important to develop an understanding of the potential barriers and enablers to provision of such healthcare. This has been an under-researched topic to date. Our aim was to examine the potential barriers and enablers to minimising treatment burden and maximising patient capacity as viewed by stroke care, managers and health professionals.

Methods

A stakeholder panel consisting of stroke survivors and health professionals was involved throughout the design, undertaking and reporting of this study. Ethical approval was granted by the University of Glasgow, College of Medical, Veterinary & Life Sciences (MVLS) Ethics Committee (Project no. 200170014).

Recruitment of participants

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 Managed Clinical Network, the Scottish Stroke Nurses Forum and the Scottish Stroke Allied Health Professional 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.

Data collection

Semi-structured face-to-face qualitative interviews lasting approximately 30-60 minutes were conducted by an academic GP (JK) between January and July 2018. The participant information sheet, interview schedule and consent forms are available in Appendices 1, 2 and 3. The interview schedule was underpinned by our conceptual model and taxonomy of stroke survivor treatment burden from previous work [8 10] and by Burden of Treatment Theory [2]. Interviews were digitally recorded and transcribed verbatim. No further interviews were conducted once data saturation had been reached i.e. no new themes arose during analysis.

Data analysis

Data were analysed using thematic analysis; a method for searching, identifying and analysing patterns of meaning or themes, in a dataset[13 14]. Thematic analysis has six phases: familiarization with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report[13]. In our data analysis we followed a hybrid approach of qualitative methods of thematic analysis, drawing upon both inductive (i.e. data-driven) and deductive (i.e. based on pre-conceived ideas) approaches. This was an iterative and reflexive process with the data collection and analysis being conducted concurrently. 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[13].

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 emerged 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.

Patient and public involvement

The Research Advisory Group that guides this programme of research includes four stroke survivors or carers of stroke survivors. Their input has helped to guide the aims, objectives and methods of this study.

Results

Participant details are provided in Table 1. We identified five overarching themes that capture the factors described by health professionals and health service managers as influencing the minimisation of treatment burden and maximisation of patient capacity following a stroke. One key finding was that the factors identified were described as influential on the ability to provide person-centred care which in turn influenced treatment burden and patient capacity (see Figure 1). The five themes uncovered were: healthcare system structure; resources; knowledge and awareness; availability of social care; and patient complexity. Tables 2 and 3 detail the barriers and facilitators respectively to providing care that minimises burden and maximises capacity within each overarching theme. Below we describe and discuss pertinent factors that were commonly reported by participants.

Healthcare system structure

Participants reported that the structure of the healthcare system they were operating in was hugely influential on their ability to provide low-burden, personalised care. This included the systems and processes in place to allow communication and co-ordination between health professionals, and to encourage autonomous working with flexibility in care provision.

A key obstacle identified by most of our participants was the lack of standardised communication procedures between and within work settings (i.e. hospital and community settings; primary and secondary care; health and social services). This issue was raised particularly by interviewees who work in the hospital setting, who seem to be in greater need of more structured communication procedures, for example between health and social care:

> *As a consultant you are asking: has the referral been made, has it been received? Has someone been appointed, have we heard from them? […] We are having to just constantly seek where we are up to on that process so there is no online information about where any of that is. It's all communicated by telephone. It's all proactive social workers who may update the ward, otherwise the ward is chasing*

> *that information. It's quite labour intensive to see where we are up to with things. Participant 14*

Several interviewees, especially stroke consultants, reported that communication and coordination between health professionals can be particularly problematic in the discharge process:

> *It's sometimes quite difficult to track down social workers and to get the information that you need from social workers and perhaps to get access to them at a good time for patients as well. And I think a lot of discharges are delayed because of difficulties with that side of things. Participant 9*

Most participants highlighted the importance of a system that fosters good communication between health professionals as well as collaborative working, for example regular face-to-face multidisciplinary meetings and case conferences in the hospital setting:

> *In the inpatient setting I think the multi-disciplinary model helps because you have then got not just a physician view of the world, you've got the nurses and the therapists talking about the person's other limitations and if you have got a really good named nurse that will often know the sort of psychological concerns the person has as well. So you will get a really, a much more complete picture. So I think that works well although I was going to say it's time consuming but it's probably only you know these meetings are maybe only a bit over an hour a week all told for the stroke unit so I think that's a big plus. Participant 11*

Participants also described working in an inflexible system where health professionals were discouraged from working autonomously due to rigid protocols and procedures. This opinion was expressed by more senior health professionals (i.e. 5+ years in the job). This prevented the provision of individualised care as they felt unable to tailor care to their patient's needs.

Resources

Resources in both the hospital and community were highlighted as important. A key resource issue in the secondary care setting was nursing staff shortages on the wards. This was raised by virtually all participants working in the hospital setting, irrespective of their profession:

> *The nursing staff are short staffed, they don't have two people that can walk round to the toilet so they use the machine called the steady to take them to the toilet which is a much easier, quicker way for them to do it but then that cuts back on that rehab potential so there is those kind of issues I would say but I think that harps back to probably the staffing issues overall. And having the time. I think the nurses don't have time to be rehab nurses. Participant 3*

Limited access to in-hospital investigations was highlighted by almost all stroke consultants, which was reported as delaying progress of recovery and prolonging hospital stays. A shortage of psychologists in the community was also reported by almost all participants working in the community and this was described as having a detrimental impact on stroke survivors' self-efficacy and ability to adjust to new disabilities or other difficulties. Despite shortages in the community, many participants working in the hospital setting praised the availability of in-house stroke-dedicated psychology services:

> *We have a strong and very healthy stroke psychology team in Glasgow and I think I'm really pleased with the extent to which that team works as part of the multi-disciplinary stroke service. I think it becomes a bit more fragmented when it goes in, when you come back into the community. I'm thinking about in an acute environment. From an acute perspective we have got a very good stroke/psychology team. Participant 19*

Knowledge and Awareness of both Patients and Professionals

Participants acknowledged that increasing stroke survivors' knowledge of the treatments and services available to them could lessen their treatment burden. They identified several factors that can hinder the successful transfer of information. One important obstacle identified by almost all stroke consultants and both health service managers was the difficulty in providing person-centred information at the right time for the patient. For example, secondary care professionals described a lack of one-on-one time with patients and that any such time was limited to during the acute phase of stroke when retaining information may be difficult:

> *It would be great if there was more of a person assigned to you and you saw them right through the journey or you had a contact point who you could regulate input information if you needed to. I don't know if it would be easy to work but that would probably be an ideal from a patients' point of view. Participant 1*

They reported that health professionals' knowledge was also important, for example it was felt by some in the hospital setting that those working in social services and primary care may lack specialised knowledge about stroke recovery.

Stroke nurse, pharmacist and volunteer visits to stroke survivors on the ward and in the community were deemed to be important facilitators of increasing patients' knowledge and awareness of services:

> *We are fortunate here that we've got stroke nurse specialists who are sort of board employees and we've got two in 'x hospital' and one up at 'Y hospital' where our rehab unit is. All of the Greater Glasgow and Clyde hospitals have stroke nurse specialists and one of their specific roles is information provision to patients and their families. Participant 15*

The existence of a written information booklet that had been made available by the health board called the 'My Stroke booklet' was highlighted by many participants, particularly stroke consultants and nurses, as a helpful source of information to distribute to patients. However, a few of the interviewees indicated a shortage of these booklets in their work settings.

Availability of social care

Inconsistent or insufficient provision of social services in the community was mentioned by more than half of the participants working in the community setting:

> *Depending on the area that the person lives in, depends how quickly homecare get puts into place. So 'area X' is good, 'area B' is not. So we have to be very proactive about saying to 'area B' come on, come on these people need this and they need it now but it might not go onto place quickly. Participant 13*

The important role of informal social networks such as friends and family were highlighted as very important following discharge into the community:

> *Social networks can have a very positive or a negative impact on patients. You know, if people are isolated then they might find it harder to be able to manage their long-term condition. But I think certainly a lot of the successes we see are with patients who have got more supportive networks. Participant 12*

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.

Patient Complexity

Many interviewees, particularly those working as physiotherapists, highlighted that it could be challenging to provide suitable, individualised care to those with complex post-stroke cognitive, physical or psychological difficulties:

> *There is always a challenge getting the right information to patients at the right time and I think with stroke patients that's particularly challenging because of the emotional issues immediately after a stroke and the cognitive issues and that the language issues obviously some people can't read information and taking on new information is very difficult. You are talking about patients with language problems, cognitive issues, their life turned upside down so they've got all sorts of psychological problems. Participant 9*

Patient self-efficacy was commonly reported by those working in the hospital setting as influential on how care was provided, for example, shared decision making was easier in a patient with confidence in achieving their goals. Multimorbidity and polypharmacy were another challenge cited by several participants working in the hospital setting, particularly stroke consultants, due to the increased workload of healthcare experienced by patients with multimorbidity and the increased risk of treatment interactions.

For complex patients, ensuring a sense of continuity throughout the rehabilitation process was deemed to be important to minimise treatment burden. Hence, the majority, particularly those working as physiotherapists, highlighted the importance of a named stroke nurse, or other designated person, throughout the patient journey:

> *If [stroke survivors] even had somebody they could phone or somebody came out to their house after they were home and said you know, these are the things that might happen or [...] if you have got any concerns or problems give us a phone. I think there should be regular contact, not necessarily with the stroke nurses in the hospital but again through health centres or GP surgeries or whatever they should be, a stroke nurse or somebody similar who can get into the community and just, not necessarily know everything about it but be able to say this is the number you can call.*
>
> *Participant 4*

More experienced health professionals (i.e. 10+ years in job) noted that in recent years the role of the stroke nurse has been limited to the hospital setting, with rare visits in the community environment. This was felt to be an important resource issue that has negatively impacted on the provision of care for complex patients.

Discussion

Summary of findings

This is the first study to explore health professional and healthcare managers perspectives on barriers and facilitators to providing healthcare that is minimally burdensome for stroke survivors whilst enabling their recovery. Five major factors were reported as being influential on providing low burden healthcare: healthcare system structure; resources; knowledge and awareness; availability of social care; and patient complexity. These factors were reported as influencing treatment burden and patient capacity through impacting health professionals' abilities to provide 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 making 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. Many participants described working in an inflexible system where communication and co-ordination between specialities is substandard and key resources such as ward nursing staff and community psychologists are lacking. Educating patients about their treatments was felt to be very important, yet the interviewees often reported difficulties in obtaining the time and materials to adequately do this. Patient complexity was acknowledged as becoming increasingly common and having a major impact on the way health care is provided, for example it may be harder to minimise treatment burden and maximise patient capacity in a frail patient with multiple long-term conditions. Deficiencies in the availability of social care was reported as an important factor affecting patient capacity, particularly if the patient lacked an informal social network who could help them manage their health. All participants acknowledged the importance of providing healthcare that minimises treatment burden and maximises patient capacity, yet they often felt they were prevented from being able to do so by the health and social care system that they worked in. Findings suggest that changes at the macro level are needed to foster an environment that supports the provision of person-centred, low-burden care for stroke survivors. Commonly suggested improvements made by participants to overcome the barriers reported are presented in Table 4. 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.

Strengths and limitations

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. One key strength was that data saturation was reached, another was the inclusion of health professionals across the stroke survivor journey, from acute through to primary care. Double coding of a subset of interviews enhanced coding reliability.

How does this compare to previous research?

Treatment burden is a relatively new concept in the medical literature that has been infrequently examined in stroke. While this is the first study to examine professional perspectives on barriers and facilitators to reducing treatment burden and maximising capacity in those with stroke there has been some published literature on this in relation to patient perspectives. We previously conducted a large systematic review of the qualitative literature [10] and conducted our own qualitative study [8] to examine the patient experience of treatment burden in stroke and the factors that influence patient capacity. The aspects of care that stroke survivors described as being influential on treatment burden and patient capacity were very similar to those reported here by health professionals: substandard information provision; poorly co-ordinated care, particularly during discharge from hospital into the community; a lack of continuity of care; long waiting times for investigations; and poor access to psychological services in the community. Both health professionals and stroke survivors emphasised the importance of person-centred care. Another recent systematic review examined stroke survivors' and their caregivers' experiences of community healthcare [15]. Although focussed on care in the community and not aimed at examining treatment burden, findings again resonated with professional perspectives reported here in that stroke survivors reported continuity of care, access to psychological services, information provision, access to social care, communication between services and fluidity of care as influential on their experience of healthcare. A recent meta-review examined systematic reviews of qualitative studies that had examined the experience of self-management for stroke survivors[11]. Again, patients identified similar issues to those we have found with health professionals in this study, particularly relating to the varying needs across the patient journey and a requirement for better information provision, social care, patient -professional communication, and psychological support in the community. The similarities in findings between these previous studies of stroke survivors and our current study of health professionals strengthens the argument for system-level change in the way we provide healthcare that allows health professionals to deliver person-centred care.

What further research is needed?

Findings from this study of health professionals and our previous examination of the patient experience of treatment burden highlights the need to develop interventions aimed at minimising treatment burden and maximising capacity in those with stroke. The current study should inform the development of such complex interventions. Examples of potential interventions include: introduction of electronic systems to enable better communication between specialties; a named person throughout the patient journey (both in the hospital and the community); a routine review in primary care soon after discharge from hospital; or online access to a stroke community for peer support. To ascertain if such interventions are successful, it is important to be able to measure treatment burden in those with stroke, and therefore development of a patient-reported measure of treatment burden for this patient population is required. PRMs of treatment burden have recently been developed for use in other patient groups [16-18] and augmentation of these with validation in a stroke population may be suitable.

Conclusion

This study gives insight into the perspectives of healthcare managers and professionals regarding the barriers and facilitators to providing healthcare that minimises treatment burden and maximise patient capacity to manage health.

Findings resonate greatly with our previous studies of the perspectives of stroke survivors[8 10]. A key finding was that the provision of person-centred care is fundamental. The findings should be used to inform the development of future complex interventions aimed at minimizing treatment burden for stroke survivors and maximising their capacity to manage health problems.

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Author contributions

KIG and FSM contributed to the design of the project. JK conducted the interviews. DS conducted data analysis and JK double coded a subset of the transcripts. KIG, FSM, DS and JK all took part in coding clinics. DS and JK wrote a first draft of the paper and all authors reviewed drafts and approved the final version.

Competing interests

KIG received funding from The Stroke Association to complete this work. FSM received payment for educational activities from Janssen outside the submitted work.

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Data sharing statement

Data are available upon request to the corresponding author. As data contain information which may lead to the identification of study participants, funding would be required to support anonymisation of the data.

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Table 1 Participants' profile

	Age			Gender		Years in job			Work environment		Profession							
	18-34	**35-50**	**51-69**	**M**	**F**	**1-5**	**5-10**	**10+**	**Hospital**	**Community**	**Stroke consultant**	**Physio**	**Stroke nurse**	**Health service manager**	**GP**	**SALT**	**Psychologist**	**OT**
Number of Participants	1	15	5	6	15	5	7	9	16	5	5	5	3	2	2	2	1	1

Table 2 Barriers to providing health-care that minimises treatment burden and maximises patient capacity

Theme	**Structure of Healthcare System**	**Resources**	**Availability of Social Care**	**Patient Complexity**	**Knowledge and Awareness of both Patients and Professionals**
Barriers	*Communication and co-ordination between health professionals:* disjointed electronic systems; lack of standardised communication procedures yet rules around using informal avenues; poor coordination during the discharge process; lack of a names nurse that links hospital and community care. *Lack of autonomy for healthcare professionals:* rigid protocols; feeling of disempowerment; inflexibility in support and follow up that can be offered; rigid post-discharge readmission procedures.	*Hospital :* ward nurses; stroke-specialist nurses; investigations; therapies; rehab equipment; beds on stroke wards; rehab spaces; patient stimulation e.g. activities on the ward; TIA clinic staff. *Community:* patient transport; rehab equipment; psychological support; facilities for physically disabled stroke survivors e.g. ramps on buses; CST staff especially psychologists and physios.	*Complicated financial support procedures:* particularly for those of pre-retirement age (65). *Inconsistent or insufficient social services* e.g. stroke clubs, home care, home adjustments. *Inadequate involvement of social networks* in the care of stroke survivors.	*Socio-economic vulnerabilities* e.g. poor housing conditions. *Lack of self-efficacy* e.g. lack of confidence in achieving goals. *Cognitive, physical, psychological and other post-stroke difficulties* e.g. poor mobility, low mood affecting progress. *Poor educational and IT literacy levels* e.g. can limit access to online resources. *Multimorbidity and polypharmacy* – higher risk of treatment burden with multiple long-term conditions.	*Lack of timely and personalised information* provision to stroke survivors. *Social care's lack of awareness around psychological difficulties* suffered after stroke. *Lack of GPs' specialisation* in post-stroke difficulties.

Table 3 Facilitators to providing health-care that minimises treatment burden and maximises patient capacity

Theme	**Structure of Healthcare System**	**Resources**	**Availability of Social Care**	**Patient Complexity**	**Knowledge and Awareness of both Patients and Professionals**
Facilitators	*Communication between health professionals:* electronic communication; pre-existing or personal contacts. *Collaborative working:* regular multidisciplinary meetings; interdisciplinary collaboration e.g. between different health professionals and services.	*Hospital:* stroke training for nurses; activities and facilities available on wards; stroke specific psychological support; opportunity for participation in clinical trials. *Community:* provision of home adaptations for physical disability; intensive and goal-driven therapy.	*Peer support* for stroke survivors and carers. *General vitality programmes* in the community. *Social network support* e.g. friends and family living locally.	*Screening for psychological and cognitive difficulties* at routine check ups. *Named keyworker* throughout the 'stroke journey'. *Patient self-efficacy*. *Shared decision-making* and visual aids that foster this. *Regular medication reviews*. *Dossette boxes*. *Consultants with geriatric backgrounds* - better able to deal with multimorbidity.	*Pharmacist visits* in the ward to provide info to stroke survivors about medications. *Written information*. *Stroke nurse* visits in the ward and community. *Chest, Heart and Stroke welfare officers*. *Online self-management tools*. *'In-house' primary and secondary care information services.* *Transparency in services available* in the community.

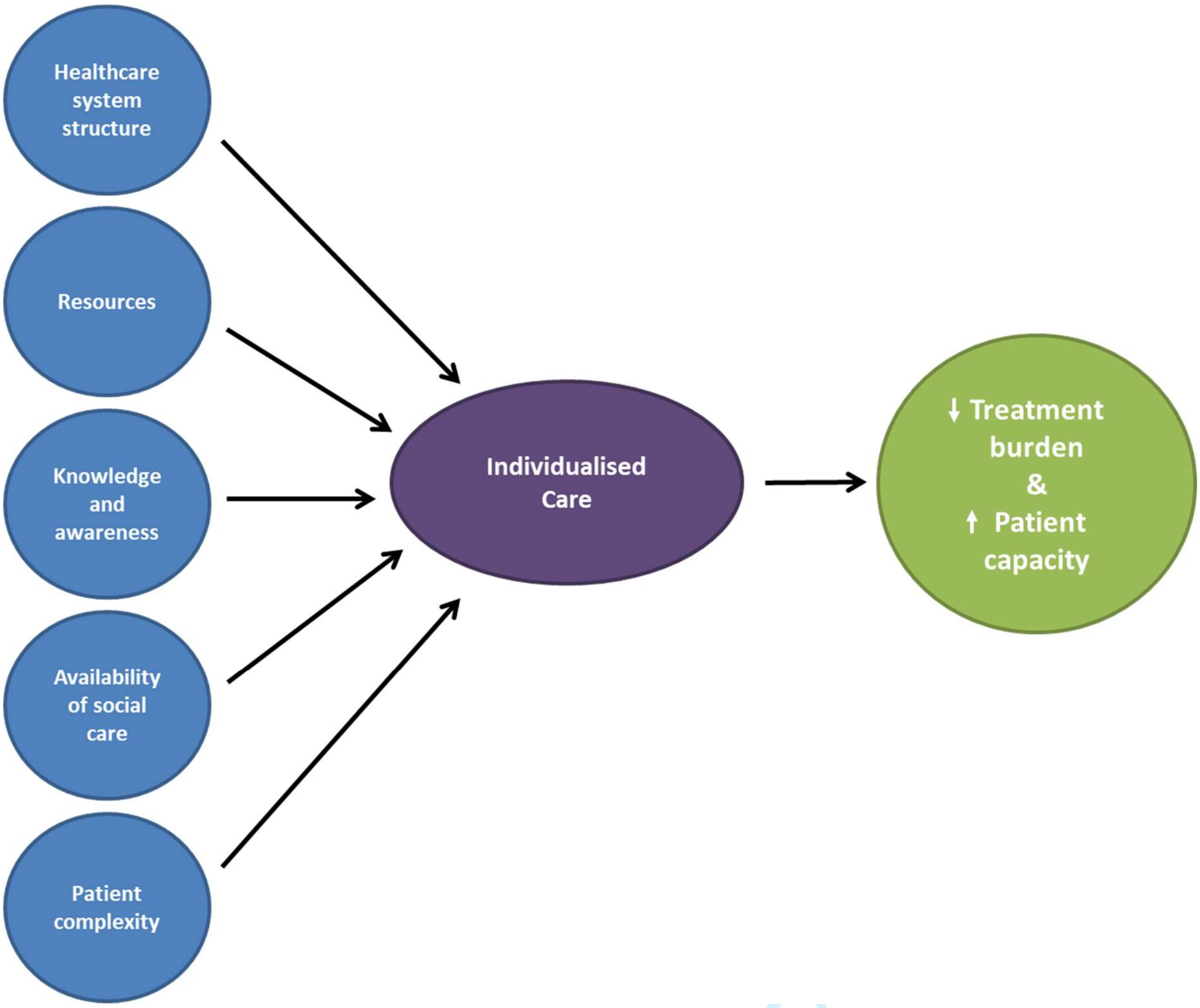
Table 4 Suggested improvements per theme

Theme	**Structure of Healthcare System**	**Resources and Provisions**	**Availability of Social Care**	**Patient Complexity**	**Knowledge and Awareness of both Patients and Professionals**
Suggested Improvements	Introduction of a named person to facilitate communication between services e.g. ‘discharge coordinator’. Autonomous working to enable person centred care. Improved communication between services and specialities e.g. ability to call a named person or meet face to face.	Investment in the provision of psychological support services in the community. Increased numbers of nursing staff in hospitals, particularly in stroke wards.	Enhancement of social network support, particularly for those with weak social networks e.g. prompt support group referral.	Routine patient follow-up reviews and medication reconciliation in the community.	Tailored information provision to stroke survivors in accessible language and format. Designated contact person throughout the 'stroke journey'.

Figure Legends

Figure 1 Areas in which treatment burden can be minimised and patient capacity can be maximised

Figure 1 Areas in which treatment burden can be minimised and patient capacity can be maximised



University of Glasgow | College of Medical, Veterinary & Life Sciences

PARTICIPANT INFORMATION SHEET

Study title

Optimising healthcare for stroke survivors - a study of health professional perspectives on minimising treatment burden and maximising patient capacity.

What is the purpose of the study?

Research has shown that people who have had a stroke can find it difficult to follow treatments recommended by their doctors, nurses and therapists. For example, medication regimes can be complicated, information on treatments lacking and communication between GPs and hospital doctors poor. This nine-month project is part of a wider programme of work aimed at developing interventions that can reduce the burden of treatment felt by stroke survivors and improve their abilities to self-manage health problems. In this project, we aim to understand from the perspective of healthcare professionals, service planners and policy makers why problems described by people with stroke may arise, and how we can develop new ways of providing healthcare for people with stroke.

Why have I been chosen?

You have been chosen as a potential participant because you either provide healthcare to stroke survivors or you are involved in the planning of this healthcare. We plan to interview approximately 20-25 people who provide stroke care or are involved in planning stroke services and policies.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form (you will also be given copy of the signed consent form). If you decide to take part, you are still free to withdraw at any time and without giving a reason.

What will happen to me if I take part?

If you choose to take part, you will be interviewed once in a location that is convenient to you, for example your place of work. The interview will last approximately one hour.

What are the possible disadvantages and risks of taking part?

You will be giving up your time to take part in this research project. Any travel expenses will be reimbursed. There is a small risk that you may find discussing certain experiences upsetting, for example a difficult clinical experience in the past or personal experience of stroke services. The person conducting the interview will direct you to your GP or local counselling services if this is required.

What are the possible benefits of taking part?

You will receive no direct benefit from taking part in this study. The information that is collected will help us better understand the factors that may prevent or enable the provision of stroke care that reduces the burden of treatment felt by stroke survivors and maximizes their capacity to manage their health. It will inform the development of future interventions for people with stroke.

Will my taking part in this study be kept confidential?

All information which is collected about you, or responses that you provide, during the course of the research will be kept strictly confidential. You will be identified by an ID number, and any information about you will have your name and address removed so that you cannot be recognized from it. Please note that assurances on confidentiality will be strictly adhered to unless evidence of serious harm, or risk of serious harm, is uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies.

What will happen to the results of the research study?

We aim to publish the results of this study in a peer-reviewed journal, and will present this work at national and international conferences. You will not be identified in any report, publication, or presentation. Articles published in peer reviewed journals are made available free of charge on the University of Glasgow website https://eprints.gla.ac.uk/

Who is organising and funding the research?

This project is being organised by the Institute of Health and Wellbeing at the University of Glasgow. The work is being funded by *(insert funder here)*.

Who has reviewed the study?

This project has been reviewed by the MVLS Ethics Committee at the University of Glasgow.

Contact for Further Information

Dr Katie Gallacher
Katie.gallacher@glasgow.ac.uk
0141 330 8323
General Practice and Primary Care
Institute of Health and Wellbeing
1 Horselethill Road
G12 9LX
University of Glasgow

What if I have a complaint about the study?

There is a standard complaints procedure which can be followed if you have any complaints related to this study. Please contact - Professor Kate O'Donnell, Department of General Practice and Primary Care, 1 Horselethill Road, University of Glasgow, G12 8RW, telephone no 0141 330 8329. This contact is independent to our study team.

Thank you for considering taking part in this study.

University of Glasgow

NHS Greater Glasgow and Clyde

INTERVIEW GUIDE: Health professional perspectives on minimising treatment burden and maximising patient capacity

Background Information for the Interviewer

In situations where there is a lack of knowledge, questions will be posed in a manner which takes account of such a limitation.

The interview will be semi-structured in format, and thus the exact wording and prompts used may vary between participants to encourage them patient to share their views.

Introduction Procedure with Patients

1. Give complete name.
2. Identify self as a researcher from the Department of General Practice and Primary Care at the University of Glasgow.
3. Give short explanation of the purpose of the study:

'I would like you to help me understand the factors that influence how you plan or provide healthcare for stroke survivors. I am interested in particular about how we can provide healthcare that minimizes the burden on stroke survivors and maximizes their capacity to manage their own health. Please feel assured that no one will be able to identify you from what you say when talking to me and everything you tell me will be treated in the strictest confidence. As findings are recorded, please do not state the names of any patients or other identifiable information during the interview'

13/9/17 Version 2

If at any time you want to stop, or have a break, please feel free to let me know.

'I will be recording the interview, so I can remember all that you have said to me.'

PARTICIPANT PROFILE

Subject ID:

Age:

Gender: Male ( ) Female( )

Profession:

Stroke consultant	( )
Stroke doctor in training	( )
Stroke nurse	( )
Physiotherapist	( )
Occupational therapist	( )
SALT	( )
Psychologist	( )
Practice nurse	( )
GP	( )
Policy maker	( )
Health service manager	( )
Other	( ) Please state:

Do you work in the:

Hospital Setting	( )
Community	( )
GGC offices	( )
Government offices	( )
Other	( )

13/9/17 Version 2

How long have you worked in this job?

<1 year	( )
1-5 years	( )
5-10 years	( )
>10 years	( )
Practice nurse	( )

Date and Time of Interview:

The interviewer will therefore explore the following general areas in an open fashion:

Information provision

Do you feel that information provision is currently adequate for stroke survivors?

If not, how could it improve?

What facilitates and prevents good information provision?

Multimorbidity

Do you think that comorbidities are dealt with adequately by stroke services?

If not, how could this be improved?

What facilitates and prevents stroke services dealing with comorbidity?

Who should deal with comorbidity e.g. community stroke team / hospital doctors / primary care?

Care co-ordination

How well do hospital teams and community stroke teams communicate?

How well do primary and secondary care communicate?

How well do health and social services communicate?

What facilitates and prevents the above communication?

13/9/17 Version 2

Hospital stay

Do you feel the hospital stay could be improved for stroke survivors?

If so, how?

Do stroke survivors undergo enough rehabilitation when in hospital?

Is the nursing care adequate?

What factors would prevent and facilitate improvements to the hospital stay?

The discharge process

What are the pros and cons of the current discharge process that patients undergo?

How could it be improved?

What would facilitate or prevent such improvements?

Access to services in the community

Do you think that stroke survivors have adequate access to stroke services in the community?

If not then what services are difficult to access and why do you think that is?

What would improve and prevent better access to these services?

Medications

How could stroke survivors be helped to understand their medications better?

How could stroke survivors be helped to adhere to medications?

Are stroke survivors prescribed too many medications?

How often should these be reviewed and by whom?

Financial aid

Do you think that stroke survivors get adequate financial aid following their stroke?

If not, how could this be improved?

What factors facilitate and prevent this aid reaching stroke survivors?

Who should provide support with this process?

Shared decision making

Do you think that shared decision making is helpful to stroke survivors?

What do you think facilitates and prevents shared decision making?

Supporting the social network

Does an individual’s social network (friends, family, neighbours) influence their ability to manage their health and follow treatments?

If so, how?

How can health and social services provide social support for stroke survivors and enahnce their social network?

What factors may prevent or enhance the provision of such support?

Self-efficacy

Do health services currently promote self-efficacy in stroke survivors?

How might they do this better?

What are the potential barriers and facilitators to this?

Physical disabilities

Do health services adequately support stroke survivors with physical disabilities in the community?

How might they do this better?

What are the potential barriers and facilitators to this?

Cognitive difficulties

Do health services adequately support stroke survivors with cognitive difficulties in the community?

How might they do this better?

What are the potential barriers and facilitators to this?

Psychological difficulties

Do health services adequately support stroke survivors with psychological difficulties (e.g. low mood , anxiety) in the community?

How might they do this better?

What are the potential barriers and facilitators to this?

At close of Interview

The interviewer will ask the participant if there are any issues they would like to mention which haven't been covered.

And thank the participant, and reiterate that all they have discussed is confidential.

13/9/17 Version 2

University of Glasgow | College of Medical, Veterinary & Life Sciences

Centre Number:
Project Number: 301100
Subject Identification Number for this trial:

CONSENT FORM

Title of Project:
Optimising healthcare for stroke survivors - a study of health professional perspectives on minimising treatment burden and maximising patient capacity

Name of Researcher(s):
Dr Katie Gallacher
Prof Frances Mair

Please initial box

I confirm that I have read and understand the information sheet dated __________ (version ______) for the above study and have had the opportunity to ask questions. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐

I agree to take part in the above study. ☐

Name of subject	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

(1 copy for subject; 1 copy for researcher)

College of MVLS
Ethics Committee

Version 2 13/9/17

Initial broad thematic categories (nodes) that formed the code manual

1. Information provision to stroke survivors
2. Communication between Health & Social services
3. Support for psychological difficulties
4. Support for physical disabilities
5. Support for cognitive difficulties
6. Communication between Hospital & Community teams
7. Communication between Primary & Secondary care
8. Nursing Care
9. Dealing with co-morbidities
10. Social services support in the community
11. Medication Adherence
12. Medication Review
13. Financial Support
14. Discharge Process
15. Community Stroke Team Support (CST)
16. Hospital stay
17. Rehabilitation in the Hospital
18. Rehabilitation in the Community

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Title and abstract

	Page.
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	4
Purpose or research question - Purpose of the study and specific objectives or questions	5

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	4,6
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	7
Context - Setting/site and salient contextual factors; rationale**	5,6
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	5,6
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	5
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	6

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	6, appendices
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Table 1
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	6,7
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	6,7,8
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	7,8

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	8-15
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	8-15

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	15-18
Limitations - Trustworthiness and limitations of findings	15

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	20
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	20

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388