BMJ Open

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Journal:	*BMJ Open*
Manuscript ID	bmjopen-2019-033066
Article Type:	Research
Date Submitted by the Author:	19-Jul-2019
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Keywords:	Stroke < NEUROLOGY, fatigue, rehabilitation, QUALITATIVE RESEARCH, healthcare professional

Conceptualising Post-Stroke Fatigue: *A Clinical Perspective*

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ABSTRACT

With survival after stroke improving, more people are discharged into the community with multiple and persistent deficits. Fatigue is a common unmet need for stroke survivors, but there are no evidence-based guidelines for its assessment and management. This study explored how UK-based therapists conceptualise post-stroke fatigue in current practice.

Objective To describe current understanding of post-stroke fatigue (PSF) amongst therapists working in stroke survivor clinical settings.

Design A cross-sectional online survey using Qualtrics software (a survey creation and analysis programme) was sent to therapists working with stroke survivors. Responses to the question, 'How would you describe Post-Stroke Fatigue if approached by another healthcare professional?' were analysed thematically by two independent researchers.

Participants 137 survey respondents (71 physiotherapists, 66 occupational therapists) from a range of clinical settings (25 acute care, 25 sub-acute rehabilitation care, 3 primary care, 81 community care) with 7 months-36 years of experience working with stroke survivors completed the survey.

Results Respondents stated that post-stroke fatigue should be regarded as an important medical condition, because it is common and can be associated with severe symptoms. Symptoms were perceived to be highly variable and the syndrome was difficult to define objectively. It was felt to have both physical and cognitive components. A variety of different opinions were expressed with regard to causation, conceptualisation and best management.

Conclusion Therapists working with stroke survivors conceptualise and manage post stroke fatigue in different ways. Clinical practice is hampered by a lack of a widely adopted definition, and a small evidence base. Research into causes and treatments of post-stroke fatigue is a priority.

Key terms stroke, fatigue, rehabilitation, healthcare professional, qualitative approaches

Article Summary

Strengths and limitations of this study

- Strength: Survey design enables an efficient and nationally representative view of current clinical practice.
- Strength: Survey design removes the influence an interviewer may have on responses.
- Limitation: Targeting only a specialist sub-population of therapists who routinely deal with PSF coupled with the 8% response rate may mean our findings were unrepresentative of broader clinical practice.
- Limitation: The open nature of the survey question may have resulted in different interpretations of the study question

INTRODUCTION

Post-stroke fatigue (PSF) is a common symptom leading to unmet need for stroke survivors (1). It is a debilitating condition which adversely affects quality of life, social participation, return to work and mortality (2,3). Despite this, PSF lacks an agreed definition, gold-standard outcome measure or an evidence-based therapeutic option (4,5). It is important to develop better understanding and management of this condition. Agreeing a definition for PSF as a symptom could enable healthcare professionals and researchers to identify patients with clinically significant fatigue who may benefit from further investigation and treatment.

Previous work has sought to classify PSF into biological and psychological dimensions, and to identify primary and secondary aetiology (6). In 1891, Mosso delineated two clear aspects of fatigue, drawing a distinction between the diminution of muscular force and the sensation of fatigue. He split this into physical fatigue, which is readily measurable, and a more elusive psychological element (7). This classification continues to be used to explain a range of proposed causative processes for fatigue. Lynch and colleagues proposed the first case definition of PSF in 2007 and demonstrated its reliability and validity on stroke inpatients (8). However, this definition may be applied more widely to encapsulate all neurological fatigue as opposed to one unique to stroke.

This is the first study investigating how UK based therapists are conceptualising this clinical problem in current practice. The study aims to explore how UK based therapists perceive and describe PSF in clinical practice by answering the question "How would you describe Post-Stroke Fatigue to another healthcare professional?".

METHOD

Patient and Public Involvement

Following initial review of the literature, researcher KT visited a Cambridgeshire based stroke group to discuss community-based stroke survivors understanding and experience of post-stroke fatigue. Initial research priorities were pitched to decipher if the research questions were thought to be important to a stroke survivor population. It was clear that improving understanding and management for post-stroke fatigue should be a priority and the current study will help address patients concerns. Following this visit, lead investigator KT created the initial survey and met with specialist therapist DM to make initial alterations. This proposed survey was taken to the multi-disciplinary development group to ensure the questions were appropriate and comprehensible.

Question Development

A ten question survey on the definition, assessment and management of post-stroke fatigue in clinical practice was developed by a multi-disciplinary group (physiotherapists, occupational therapists and a clinical psychologist working in Cambridgeshire community teams). This paper focuses on a single question relating to understanding of PSF which was created by lead author KT and then discussed and refined within the development group. The questions were piloted by three physiotherapists (PT) and one occupational therapist (OT), as a result of which alterations were made. The question was revised following discussion at the questionnaire development group to specifically target a clinical population as opposed to a patient population.

Participants

Physiotherapists who were members of the Association of Chartered Physiotherapists in Neurology (ACPIN) and occupational therapists who were members of Royal College of Occupational Therapy (RCOT) Specialist Section- Neurological Practice (RCOT-NSS) and who had registered an interest in participating in related research were invited to participate. To be eligible, participants were also required to have current registration as a healthcare professional, and to have worked with stroke survivors whilst in clinical practice within the United Kingdom.

Design

A cross-sectional survey was created and answered electronically using Qualtrics software, an online survey creation and analysis site licensed to the University of Cambridge (https://eu.qualtrics.com).

Questionnaire Distribution

The research lead from each national organisation (ACPIN and RCOT-NSS) distributed an initial invitation email to members who had expressed an interest in participating in stroke-related research. Within the email was a participant invitation including a link to the Qualtrics platform which provided a participant information sheet and a consent form. Respondents entered their answers directly on to the Qualtrics online platform. After two weeks, a reminder email was sent to individuals who had not completed the survey. The survey remained live for one month following the reminder.

Data analysis

Submitted survey responses were collated on the Qualtrics platform and downloaded using https secure protocol to the Secure Data Hosting Service at the University of Cambridge. This data was then anonymised and loaded into Microsoft Excel. Responses to question 5 “How would you describe Post-Stroke Fatigue if approached by another healthcare professional?” were analysed thematically by two independent researchers KT and CH, aiming to identify all pertinent themes. KT and CH first familiarised themselves with the data set. Both researchers coded 5% of the data initially to ensure a systematic coding strategy, then 40% of posts were randomly selected and coded by researcher CH while the remaining 60% were coded by KT. After all data had been coded, both researchers met and discussed the allocated codes, re-coding the data until unanimous agreement was reached. Codes were then grouped into sub-themes which were organised to create a thematic model. All responses were checked by both researchers to ensure all data fitted into the model. Descriptive statistics were used to analyse respondent characteristics and decipher frequencies within the data set.

RESULTS

Participant Characteristics

700 occupational therapists and 800 physiotherapists were sent a study invitation email of whom 137 individuals completed the survey. Responses varied considerably in length from 2 to 148 words. with a median of 49 words. Occupational therapists and physiotherapists responded in similar numbers (66 occupational therapists, 71 physiotherapists). Respondents had experience working in a variety of

settings with stroke survivors, identifying as working in: acute care (25 respondents); sub-acute rehabilitation care (24); community care (85); and primary care (3). The duration of specialism individuals had in stroke ranged from 7 months to 33 years (Table 1).

Participant respondents	Number
Profession	
Occupational therapist	66
Physiotherapist	71
Clinical setting	
Acute	25
Sub-Acute	24
Community	85
Primary Care	3
Duration of specialism	
< 1 year	4
1-5 years	29
6-10 years	41
11-15 years	17
16-20 years	19
21 + years	27

Table 1: Respondent characteristics by profession, clinical setting and duration of specialism

Themes

Overview: An Important Medical Condition

The survey question, ‘How would you describe Post-Stroke Fatigue if approached by another healthcare professional?’ generated a diverse range of responses, which can be broadly represented by the following themes. Firstly, respondents highlighted that PSF is a serious and common condition, experienced differently by individual patients. Secondly, the responses emphasised that PSF is a medical condition that should be recognised as a legitimate symptom of stroke. Finally, therapists’ acknowledged there were differences approaches to how healthcare professionals define and conceptualise PSF and also exhibited varying personal levels of understanding through their answers to the research question.

[Figure submitted seperately to main text]

Figure 1: A visual representation of key themes arising in answer to the question ‘How would you describe Post-Stroke Fatigue to another healthcare professional?’

Important: *Challenging, Common and Variable nature*

There was consensus among responses that PSF was debilitating and deeply pervasive among stroke survivors. Respondents described PSF by using the descriptor 'overwhelming', and various other words to that effect. The term 'debilitating', and descriptors such as 'all-consuming', 'extreme', and 'tiredness like no other' were typical.

Challenging

Descriptive language was a marked feature of the responses, as therapists responded creatively to the challenge of explaining the difficulties of PSF to colleagues. Further, respondents highlighted the challenging nature of PSF and the effects this had on their patients. Answers stated, 'patient's[sic] often feel like they are 'thinking through mud' [OT09] and 'pulling heavy boots on' [OT32]. Others emphasised the traumatic nature of PSF, describing it as 'hitting a brick wall' [OT62], and 'like your brain had been in a washing machine on a spin cycle' [OT47]. Medicalised metaphors were also used, one of which likened the fatigue to 'sensory overload' [PT04].

Extended analogies were employed to convey the experience of living with PSF. One response suggested, 'I sometimes describe it as a bruise on the brain, and if you imagine a bruise on your ankle, you can see it's[sic] sore and stiff and you can't walk much before needing to rest' [OT27]. One respondent directly referred to using 'the spoons analogy'[OT58]. Coined by Christine Miserandino in 2003 to describe her experience of lupus, 'Spoon Theory' explains fatigue associated with chronic medical conditions by referring to having only limited number of 'spoons' of energy that the patient can 'spend' during the day (https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/). In a similar manner, another reported, 'I describe the brain/body has having a 'battery' just like a car…Post stroke the battery can be less full to start with, can be used up more quickly than usual and can take longer to recharge and not always fully' [PT08].

Common

Pervasiveness was highlighted as a key issue; respondents typically used the terms 'common', 'very common' and 'extremely common' to describe PSF, often to start their response. Efforts to quantify this frequency were mixed; one answer asserted that PSF 'affects nearly all stroke survivors' [OT55], and another that '[PSF] affects a large number of patients, approx.. 25% [are] experiencing severe fatigue with a further 25% experiencing moderate fatigue' [PT47]. Another felt that, 'Following stroke approx. 75% of patients experience fatigue as a symptom' [OT25].

Variable

Respondents emphasised the complex and variable nature of PSF as a condition, describing it as having several components or affecting multiple aspects of a patients' life. Respondents attributed PSF to 'a mix of physical and emotional factors' [OT03], or provided more detailed causative processes, such as 'hormones, neurotransmitters and cognitive load…exacerbated by secondary factors such as diet, sleep, medication' [OT28]. The impact of PSF was also described as 'holistic', with multiple categories ('physical and cognitive') or specific aspects of impact ('adversely effects patients sleep, appetite, motivation [sic]' [PT25]).

Furthermore, respondents described the manifestation of PSF as particularly pernicious. Several reported that the fatigue experienced by stroke survivors was disproportionate to the cerebrovascular accident that had occurred, saying, '[PSF] has the highest impact in the least neurologically/physically impaired stroke patients' [PT16]. One respondent described patients as only experiencing PSF when 'they start trying to get back to everyday activities' [OT56], and several indicated that fatigue affected patients' ability to communicate with their family.

A Medical Condition: Legitimisation

Medicalisation of Symptoms

Responses emphasised the medical nature, and thus legitimacy, of PSF as a condition. PSF was described as a 'condition' or 'symptom' of stroke, from which patients were 'suffering'. Some respondents explicitly differentiated PSF from tiredness, writing that PSF was ‘completely different to “normal” tiredness’ [OT11] or ‘not the same as being tired’ [OT32, PT18]. Similarly medicalising were efforts to quantify the fatigue, with respondents employing phrases such as ‘it can be measured, monitored, and energy conservation strategies applied’ [OT22].

Scientific language was used to support these assertions; participants attributed PSF to processes of damage and healing in the brain. Neurological explanations given for PSF included, ‘the brain reorganising connections’ [OT24], ‘[PSF happens] as neuroplasticity occurs’ [PT26], and PSF being ‘caused by the effect of stroke on hormones, neurotransmitters and cognitive load’ [OT28]. One respondent attributed fatigue ‘in-part to impairment of the regulatory systems in the brain - disruption to the network connections’ [OT54].

Applying a framework

In the absence of an existing formal classification framework, respondents offered a variety of systematic approaches to organise PSF into a number of constituent causes or effects. These included classifying fatigue into ‘peripheral’ vs. ‘central’, and ‘primary’ vs. ‘secondary’. This is typified by the following response: ‘there is usually a primary (i.e. central, or disease-specific) mechanism and a secondary (loss of fitness/function, mood/sleep related etc) mechanism at work’ [OT64].

Different Clinical Approaches

There was variation in understanding between therapists, which was both explicitly identified by respondents acknowledging differences and implicitly conveyed by variation between responses highlighting different levels of understanding.

Several respondents highlighted the different approaches within their multi-disciplinary teams (MDT). One therapist wrote, ‘The doctors sometimes prescribe the patients modafinil … patients are often reviewed by the psychologist and the fatigue can be identified but I think there is a universal lack of knowing the best way to treat these patients’ [PT24]. A community physiotherapist highlighted this difficulty more explicitly, writing, ‘I do sometimes feel that OT & PT can give slightly conflicting messages. I appreciate that pacing is important, but sometimes [phrasing] can be very vague and misinterpreted...I often explain this …the OTs tend to be much more likely to encourage patients not to over do things [sic]… it can be a very tricky balancing act’ [PT33]. Another community-based physiotherapist asserted that, ‘[There are] different approaches in each discipline. OT[s] have most knowledge on fatigue management. Nursing and psychiatrists have the least knowledge and skill set to [manage] fatigue’ [PT48].

In addition to the acknowledgement of divergent opinions between health practitioners, there were substantial differences in the terminology used to define PSF. Respondents presented definitions that directly contradicted their peers. Key points of difference were whether PSF was ‘fatigue’ or ‘tiredness’, whether fatigue was related to activity undertaken, and to prognosticate.

Tiredness or fatigue?

The majority of respondents distinguished between the concept of ‘tiredness’ and fatigue’, or defined fatigue as a particularly intense variant of tiredness (‘tiredness like no other’), as previously discussed. That these comments typically occurred at the start of the response suggests that this distinction was considered important. Other responses used the terms ‘tiredness’ and ‘fatigue’ interchangeably, for example, ‘A tiredness that is not replenished by sleep and…can be physical, mental and emotional fatigue’ [OT63]. In other responses, it was unclear whether the terms were used synonymously (‘feelings of mild to extreme tiredness’ [PT32]). Some respondents appeared to define fatigue by its speed of onset, defining fatigue as, ‘feeling very easily tired’ [OT09] and ‘[to] get tired very quickly’ [PT54].

Role of activity?

Though there was consensus that fatigue had a serious effect on patients' abilities to carry out activities of daily living (ADLs), there were similar inconsistencies between therapists in relating fatigue to activity. Some respondents wrote that PSF could 'not be attributed to activity' [OT03] and was 'not related to the level of activity a person undertakes' [OT20]. One felt PSF was 'characterised by not being associated with recent levels of activity' [OT31]. Conversely, others felt that the key to managing fatigue was to 'understand...how activity affects these [energy] levels' [OT22], and use 'pacing' as a strategy. Some responses were more equivocal, writing 'impact is not necessarily related to activity levels' [PT16] or 'not always linked to activity completed' [OT32]. Others indicated that fatigue was disproportionate to activity.

Although response variation existed in how to most effectively incorporate rest into a management programme, respondents consistently referred to rest when defining PSF. It was clear that therapists felt rest or a lack thereof affected patients' experience of PSF and should be considered when assessing for clinically significant fatigue. One stated 'the best thing is to encourage the person to take complete rest...before doing anything else' [OT12], whilst others agreed; the fatigue 'reduces over time if adequate rest [is] taken [PT63]' and that it 'requires frequent rest periods' [OT23]. Others mentioned rest but conversely were of the opinion that the condition 'does not necessarily resolve following rest' [OT06] and is 'not eased by rest' [OT31]. Others framed it as more of a diagnostic symptom, stating that PSF is 'an absolute need to sleep and rest' [PT55].

Timeframe?

Finally, there was a marked discrepancy between responses offering a timescale for PSF. Respondents suggested that PSF, 'lasts…from weeks, to months to years or permanent' [PT06], 'usually improves 1 year to 2 years post stroke' [PT53], and 'may [last] for several months or even years' [OT56]. Similar in style were the responses, 'inability to participate in physio sessions longer than 15-20 mins' [PT55] and 'usually improves 1 year to 2 years post stroke' [PT53]. Other responses addressed progression more vaguely, describing PSF as 'ongoing', or lessening 'with time'. Again, these discrepancies suggest a degree of unconscious inconsistency in understanding and clinical practice.

Differences by professional background

No differences were found between occupational therapists' and physiotherapists' understanding of PSF, though physiotherapists used medicalised terminology such as "symptom" and "condition" more frequently than their occupational therapist counterparts. Length of clinical experience also appeared to have little impact on responses from therapists with between 5 and 20 years specialisation in stroke. Therapists with over 20 years' experience alluded more frequently to the effect of PSF on ADLs and patient energy levels, often providing shorter and less holistic responses. Individuals with up to five years' experience in the specialism demonstrated a notably medicalised approach.

We found that respondents in the acute setting typically used 'medicalised' terminology compared to those working in the community, among whom metaphor and patient expression were more common. Among the 25 respondents who identified themselves as working in acute care, answers were overwhelmingly characterised by the medicalisation of PSF, and by the conceptualisation of fatigue as a symptom of vascular injury. There was an emphasis on the frequency of occurrence of PSF. Respondents were more likely to use statistics for emphasis. Respondents who identified themselves as working in acute care tended to use terminology more similar to a 'dictionary definition' of the condition. Conversely, those working in subacute (25) or primary care (3) tended to define stroke in terms of its lived impact, particularly with regard to rehabilitation and the effect of PSF on specific tasks, effort and rest. Subacute and primary care-based respondents were more likely to describe PSF in terms of impact on daily life and patient engagement with rehabilitation sessions, or in a holistic manner.

The majority of respondents identified themselves as working in a community setting (81). These responses were characterised by a focus on the clinical management, lived experience of PSF, and the use of metaphor. Though metaphor was a common feature of responses, it was particularly characteristic among community-based therapists. Several community-based respondents relayed patient descriptors of fatigue as part of their definition, such as 'trying to "think through treacle"' [OT18]. Almost all respondents who commented on variation in definitions and limitations to a common understanding of PSF, identified themselves as a community therapist. Though responses from this group displayed the most variation in definition of the key features of PSF, this was likely affected by the disproportionately large sample size.

DISCUSSION

Principal Findings

Respondents portrayed PSF as a highly debilitating condition which deserved greater attention. Respondents addressed the stigma associated with this 'invisible' condition both explicitly and implicitly, with many identifying medicalisation as the most appropriate method to counteract this. Metaphor was used to convey the serious and debilitating nature of PSF. There was notable variation between different therapists' definitions and characterisations of the condition in the contradictory views expressed regarding key features of the condition. There was a lack of clarity among therapists' approaches towards the definition and appropriate use of the terms 'tiredness' and 'fatigue'. Collectively, this suggests that there may be variation in the understanding of PSF between healthcare professionals, which could suggest inconsistencies in education and terminology used in clinical practice, perhaps as a result of current training and research. These discrepancies, and the numerous calls for greater understanding and standardisation of PSF management, suggest that therapists see PSF as deserving of greater attention in training and clinical practice.

Comparison to relevant literature

In 1971, McFarland stated that 'fatigue' is one of the most used and yet most poorly understood words in the English language (9). Despite a sharp increase in published literature on fatigue over the last thirty years, and on PSF specifically in the past two decades, this appears to still hold true. When compared to other post-stroke and chronic conditions, research on PSF is still in its infancy; little research has targeted fatigue after stroke as the primary outcome, particularly regarding management and clinical understanding. It is therefore unsurprising that our respondents felt PSF was insufficiently addressed.

Collectively, the responses emphasised the importance of addressing PSF as a key post-stroke morbidity, and doing so in a holistic manner. Inclusion in clinical guidelines might improve recognition and guide practice. However, it is only recently starting to be included within prominent clinical guidelines(10-12). As Eilertsen and colleagues argue, this lack of coverage may reflect the relative lack of high quality research in the field (13). In order to legitimise PSF, therapists emphasise its medical nature, and direct causative relationship with stroke. As Young et al. have demonstrated, medical language increases perceived severity and condition representativeness, especially for less well-known conditions (14,15). Similarly, the approach of breaking down PSF into constituent components that we observed may suggest efforts by therapists to apply structure to PSF and bring it within the remit of active clinical management.

The extent to which therapists legitimise a patient's symptoms can play a significant role in how the individual understands and navigates their condition. This is reflected often in fatigue literature; patients with rheumatoid arthritis report fatigue as overwhelming, uncontrollable and ignored (16), and studies indicate that it rarely forms a treatment target. By contrast, a survey of cancer-specialist therapists found that all professional groups overestimated the effects of fatigue compared to patient reports (17), though this may have been affected by the low response rate and degree of specialisation of the respondents involved. How far therapists engage with PSF may vary within a team; the researcher team did not anticipate that the study question ('How would you describe Post-Stroke Fatigue to another healthcare professional?') would prompt discussion of the tensions involved in treating PSF within an MDT, indicating that this may be a particularly pertinent issue.

Though several qualitative studies have focused on stroke survivors' understanding of PSF, previous literature has not examined healthcare professional understanding. Throughout the survey responses, metaphor and simple descriptive language were commonly used to emphasise the impact of PSF on stroke survivors. This could suggest the central position of patient experience in clinical thinking around PSF. Several of the core characteristics identified by Eilertsen et al's model of stroke survivors' experiences of PSF (13) resonate with how therapists in our dataset understood and defined the condition. In both studies, individuals described PSF as an 'invisible disability' associated with stigmatisation, related fatigue to an 'abnormal' need to rest, and highlighted the lack of understanding and definition regarding PSF. Indeed, the authors felt that the 'medicalisation' identified in this dataset was employed to combat the evident stigma of PSF.

Education and empowerment through information has become a topic of debate for many therapists and patients over the past decade, especially with the rise of internet usage and patient-centred care model. However, this comes with its challenges. Health information literature to date has favoured a bio-medical approach to informing patients, leading to an arguably one-way model of understanding (18). We found that respondents in the acute setting typically used 'medicalised' terminology compared to those working in the community, among whom metaphor and patient expression were more common. Respondents across all levels of care emphasised that PSF was poorly understood. Literature on fatigue consistently highlights that therapists require more research and education regarding appropriate management, which our data supported.

Strengths and weaknesses

Surveys are a frequently used study design in healthcare research owing to their convenience, cost-effectiveness and low commitment requirement from participants (19). The use of an online survey allowed respondents to participate from far-reaching geographical locations and removes the variable influence of an interviewer on responses. This data therefore offers a valuable insight into PSF in current clinical practice. Nevertheless, the open nature of the survey question may have resulted in different interpretations of the study question, and our descriptive data is hindered by the inability to question respondents further (20). Though the survey was targeted to specialised therapists and responses were submitted by a diverse demographic of healthcare practitioners, the response rate was low, at 8%. This could mean that responses were taken primarily by healthcare professionals with greater interest and knowledge of post-stroke fatigue. Further, although PTs and OTs often lead fatigue management programmes, other members of the MDT were not invited to take part which may limit the generalisability of our findings to other healthcare professionals. Qualitative analysis enabled the comprehensive and in-depth analysis of each response, however this precludes any broader generalisations about clinical practice as a whole.

Clinical Implications

Therapists working with stroke survivors conceptualise post stroke fatigue in different ways. This suggests that clinical explanation and management may vary, also highlighting the need for a more consistent approach from healthcare practitioners in describing PSF.

In the context of literature that highlights PSF as a frequently unmet or insufficiently-met need, this paper highlights the importance of further research and supports calls for a standardised, evidence-based framework for describing and explaining PSF in clinical practice.
Clinical practice is hampered by a lack of a widely adopted definition, and a limited evidence base. Future analytical research should be considered to determine the rationale underlying respondents' viewpoints and the variation between them. A comparison of how stroke survivors and therapists understand and describe PSF could lead to a better shared understanding of the condition, and

improved patient-practitioner communication. Research into causes and management of post-stroke fatigue should be a priority.

Ethical approval

All documentation was approved by Cambridge University Psychology Ethics Committee (PRE.2017.092). We used the SRQR checklist when writing our report (21).

Acknowledgements: We are grateful to all survey respondents who took the time to participate in our research. Many thanks to Donna Malley for her guidance and clinical expertise at the inception of this project and Cambridge Stroke Group for allowing KT to conduct a PPI group prior to study commencement.

Author Contributions: KT and RM contributed to the initial design of the study. KT and CH conducted data analysis and theme creation. All authors contributed to manuscript writing and editing.

Funding: This study was funded by the Malati Kanbur Studentship fund kindly donated by Ravi Kanbur and Margaret Grieco to Lucy Cavendish College, constituent college of the University of Cambridge. JM is supported by an NIHR Senior Investigator award. Views expressed in this written publication are those of the authors and not necessarily those of the funders.

Competing interests: None declared.

Provenance and peer review: Not commissioned, externally peer reviewed.

Data sharing statement: No additional data are available.

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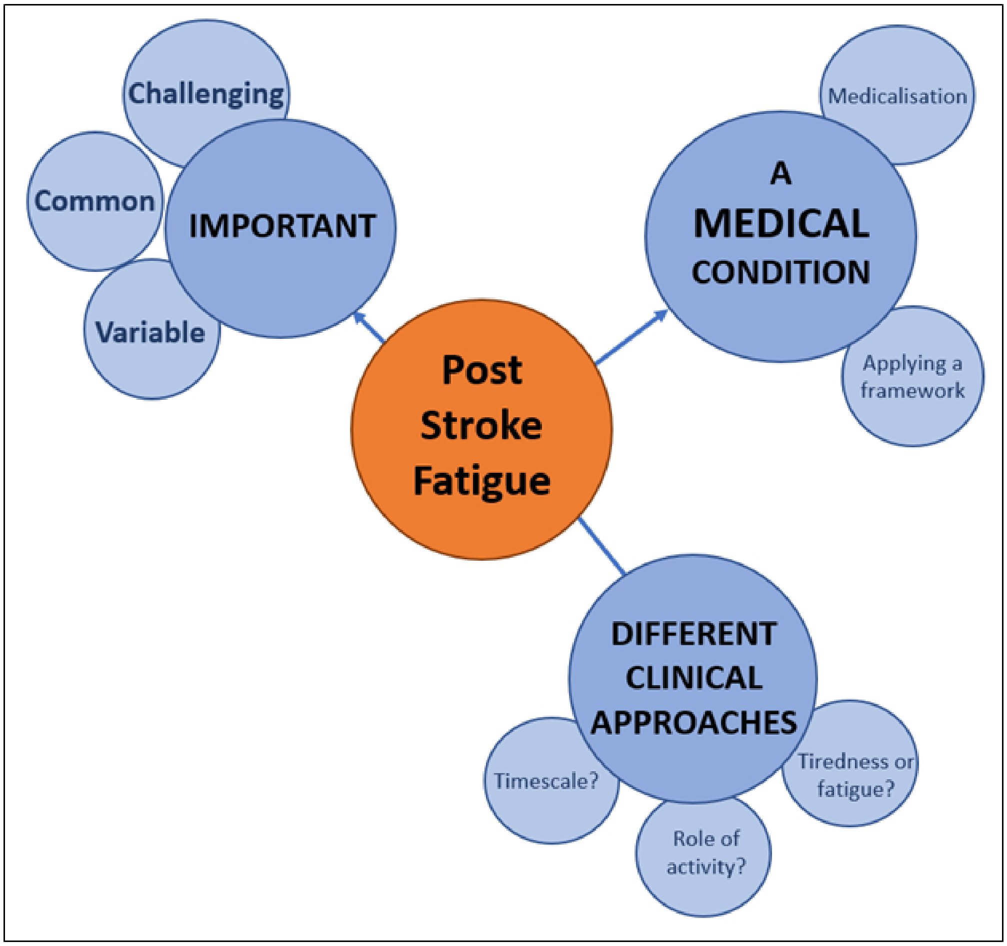

Figure 1: A visual representation of key themes arising in answer to the question ‘How would you describe Post-Stroke Fatigue to another healthcare professional?’

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

		Reporting Item	Page Number
Title			
	#1	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	2
Abstract			
	#2	Summary of the 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	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	3
Purpose or research question	#4	Purpose of the study and specific objectives or questions	3

Methods

Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. 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.	4
Researcher characteristics and reflexivity	#6	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	11
Context	#7	Setting / site and salient contextual factors; rationale	4
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling	4

		saturation); rationale	
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	11
Data collection methods	#10	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	4
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	4
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	4, 5
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	4
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers	4

		involved in data analysis; usually references a specific paradigm or approach; rationale	
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	4
Results/findings			
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	5, 6
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	6-9
Discussion			
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	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 contributions(s) to scholarship in a discipline or field	10
Limitations	#19	Trustworthiness and limitations of findings	11
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	12

Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	12

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BMJ Open

Conceptualising Post-Stroke Fatigue: A Survey of Physiotherapists and Occupational Therapists

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2019-033066.R1
Article Type:	Original research
Date Submitted by the Author:	17-Oct-2019
Complete List of Authors:	Thomas, Karen; University of Cambridge Department of Public Health and Primary Care, Public Health & Primary Care Hjalmarsson, Clarissa; University of Cambridge Department of Public Health and Primary Care, Public Health & Primary Care Mullis, Ricky; University of Cambridge, Department of Public Health and Primary Care Mant, Jonathan; University of Cambridge, General Practice and Primary Care Research Unit
Primary Subject Heading:	Qualitative research
Secondary Subject Heading:	Patient-centred medicine
Keywords:	Stroke < NEUROLOGY, fatigue, rehabilitation, QUALITATIVE RESEARCH, healthcare professional

Conceptualising Post-Stroke Fatigue: *A Survey of Physiotherapists and Occupational Therapists*

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ABSTRACT

With survival after stroke improving, more people are discharged into the community with multiple and persistent deficits. Fatigue is a common unmet need for stroke survivors, but there are no evidence-based guidelines for its assessment and management. This study explored how UK-based therapists conceptualise post-stroke fatigue in current practice.

Objective To describe current understanding of post-stroke fatigue (PSF) amongst physiotherapists and occupational therapists.

Design A cross-sectional online survey using Qualtrics software (a survey creation and analysis programme) was sent to therapists working with stroke survivors in 2019. Responses to the open ended question, 'How would you describe Post-Stroke Fatigue if approached by another healthcare professional?' were analysed thematically by two independent researchers.

Participants 137 survey respondents (71 physiotherapists, 66 occupational therapists) from a range of clinical settings (25 acute care, 25 sub-acute rehabilitation care, 3 primary care, 81 community care) with 7 months-36 years of experience working with stroke survivors completed the survey.

Results Respondents stated that post-stroke fatigue should be regarded as an important medical condition, because it is common and can be associated with severe symptoms. Symptoms were perceived to be highly variable and the syndrome was difficult to define objectively. It was felt to have both physical and cognitive components. A variety of different opinions were expressed with regard to causation, conceptualisation and best management.

Conclusion Therapists working with stroke survivors conceptualise and manage post stroke fatigue in different ways. Clinical practice is hampered by a lack of a widely adopted definition, and a small evidence base. Research into causes and treatments of post-stroke fatigue is a priority.

Key terms stroke, fatigue, rehabilitation, healthcare professional, qualitative approaches

Article Summary

Strengths and limitations of this study

- Strength: Survey design enables an efficient and nationally representative view of current clinical practice.
- Strength: Survey design removes the influence an interviewer may have on responses.
- Strength: The large number of respondents for a qualitative study means that it is unlikely that we failed to capture important themes.
- Limitation: Targeting only a specialist sub-population of therapists who routinely deal with PSF coupled with the 8% response rate may mean our findings were unrepresentative of broader clinical practice.
- Limitation: The open nature of the survey question may have resulted in different interpretations of the study question

INTRODUCTION

Post-stroke fatigue (PSF) is a common symptom leading to unmet need for stroke survivors [1, 2]. It is a debilitating condition which adversely affects quality of life, social participation, return to work and mortality [3,4,5]. Despite this, PSF lacks an agreed definition, gold-standard outcome measure or an evidence-based therapeutic option [6,7,8]. Recent qualitative work contextualising PSF from a stroke survivor and care giver perspective highlighted that acknowledgement of PSF provided legitimacy, but healthcare professionals did not approach PSF in a consistent way [9]. In order to understand why this is, it is important to gain insight into the perspective of healthcare professionals on their understanding and management of the condition [10]. Knowledge of both patient and clinician perspective can inform current fatigue management pathways.

Previous work has sought to classify PSF into biological and psychological dimensions, and to identify primary and secondary aetiology [11,12]. In 1891, Mosso delineated two clear aspects of fatigue, drawing a distinction between the diminution of muscular force and the sensation of fatigue. He split this into physical fatigue, which is readily measurable, and a more elusive psychological element [13]. This classification continues to be used to explain a range of possible causative processes for fatigue [14]. Ongoing research in the field aims to understand the aetiology and mechanisms of PSF in greater depth, as definitive conclusions have not yet been reached [15,16,17]. Lynch and colleagues proposed the first case definition of PSF in 2007 and demonstrated its reliability and validity on stroke inpatients [18].

This is the first study to investigate how therapists regard PSF in current practice by posing the question "How would you describe Post-Stroke Fatigue to another healthcare professional?".

METHOD

Patient and Public Involvement

Researcher KT visited a Cambridgeshire based stroke group to discuss their understanding and experience of post-stroke fatigue. Possible topics were informed by the current literature, including guidelines and recommendation documents [19,20]. The group gave feedback that improving understanding and management of post-stroke fatigue should be a priority.

Question Development

A ten question survey on the definition, assessment and management of post-stroke fatigue in clinical practice was developed by a multi-disciplinary group (physiotherapists, occupational therapists and a clinical psychologist working in Cambridgeshire community teams). This paper focuses on a single question relating to understanding of PSF which was created by lead author KT and then discussed and refined within the development group. The questions were piloted by three physiotherapists (PT) and one occupational therapist (OT), as a result of which alterations were made. The open ended question was revised following discussion at the questionnaire development group to specifically target healthcare professionals.

Participants

Physiotherapists who were members of the Association of Chartered Physiotherapists in Neurology (ACPIN) and occupational therapists who were members of Royal College of Occupational Therapy (RCOT) Specialist Section- Neurological Practice (RCOT-NSS) and who had registered an interest in participating in related research were invited to participate. To be eligible, participants were also required to have current registration as a healthcare professional, and to have worked with stroke survivors whilst in clinical practice within the United Kingdom.

Design

A cross-sectional survey was created and answered electronically using Qualtrics software, an online survey creation and analysis site licensed to the University of Cambridge (https://eu.qualtrics.com).

Questionnaire Distribution

The research lead from each national organisation (ACPIN and RCOT-NSS) distributed an initial invitation email to members who had expressed an interest in participating in stroke-related research. Within the email was a participant invitation including a link to the Qualtrics platform which provided a participant information sheet and a consent form. Respondents entered their answers directly on to the Qualtrics online platform. After two weeks, a reminder email was sent to individuals who had not completed the survey. The survey remained live for one month following the reminder.

Data analysis

Submitted survey responses were collated on the Qualtrics platform (https://www.qualtrics.com/blog/citing-qualtrics/) and downloaded using https secure protocol to the Secure Data Hosting Service at the University of Cambridge. These data were then anonymised and loaded into Microsoft Excel. Responses to question 5 "How would you describe Post-Stroke Fatigue if approached by another healthcare professional?" were analysed thematically by two independent researchers KT and CH. KT and CH first familiarised themselves with the data set. Both researchers coded 5% of the data to ensure a consistent coding strategy, then 40% of posts were randomly selected and coded by researcher CH while the remaining 60% were coded by KT. After all data had been coded, both researchers met and discussed the allocated codes, re-coding the data until unanimous agreement was reached. Codes were then grouped into sub-themes which were organised to create a thematic model. All responses were checked by both researchers to ensure all data fitted into the model. Descriptive statistics were used to analyse respondent characteristics and decipher frequencies within the data set.

Ethical approval

All documentation was approved by Cambridge University Psychology Ethics Committee (PRE.2017.092). We used the SRQR checklist when writing our report [21].

RESULTS

Participant Characteristics

700 occupational therapists and 800 physiotherapists were sent a study invitation email of whom 137 completed the survey. Responses varied considerably in length from 2 to 148 words. with a median of 49 words. Occupational therapists and physiotherapists responded in similar numbers (66 occupational therapists, 71 physiotherapists). Respondents had experience working in a variety of settings with stroke survivors: acute care (25 respondents); sub-acute rehabilitation care (24);

community care (85); and primary care (3). The duration of specialism individuals had in stroke ranged from 7 months to 33 years [Table 1].

Participant respondents	Number
Profession	
Occupational therapist	66
Physiotherapist	71
Clinical setting	
Acute	25
Sub-Acute	24
Community	85
Primary Care	3
Duration of specialism	
< 1 year	4
1-5 years	29
6-10 years	41
11-15 years	17
16-20 years	19
21 + years	27

Table 1: Respondent characteristics by profession, clinical setting and duration of specialism

Themes

Overview

The survey question, ‘How would you describe Post-Stroke Fatigue if approached by another healthcare professional?’ generated a range of responses which were grouped into three broad themes shown below in Figure 1: the importance of PSF; its legitimacy as a medical condition; the variety of ways in which healthcare professionals approach it.

[Figure submitted seperately to main text]

Figure 1: A visual representation of key themes arising in answer to the question ‘How would you describe Post-Stroke Fatigue to another healthcare professional?’

Important: *Challenging, Common and Variable nature*

A common response was that PSF was debilitating and deeply pervasive among stroke survivors. Respondents described PSF by using the descriptor ‘overwhelming’, and various other words to that effect. The term ‘debilitating’, and descriptors such as ‘all-consuming’, ‘extreme’, and ‘tiredness like no other’ were typical.

Challenging

Descriptive language was a marked feature of the responses, as therapists responded creatively to the challenge of explaining the difficulties of PSF to colleagues. Further, respondents highlighted the challenging nature of PSF and the effects this had on their patients. Answers stated, ‘patients[sic] often feel like they are ‘thinking through mud’ [OT09] and ‘pulling heavy boots on’ [OT32]. Others emphasised the traumatic nature of PSF, describing it as ‘hitting a brick wall’ [OT62], and ‘like your brain had been in a washing machine on a spin cycle’ [OT47]. Medicalised metaphors were also used, one of which likened the fatigue to ‘sensory overload’ [PT04].

Extended analogies were employed to convey the experience of living with PSF. One response suggested, ‘I sometimes describe it as a bruise on the brain, and if you imagine a bruise on your ankle, you can see it’s[sic] sore and stiff and you can’t walk much before needing to rest’ [OT27]. One respondent directly referred to using ‘the spoons analogy’[OT58]. Coined by Christine Miserandino in 2003 to describe her experience of lupus, ‘Spoon Theory’ explains fatigue associated with chronic medical conditions by referring to having only limited number of ‘spoons’ of energy that the patient can ‘spend’ during the day (https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/). In a similar manner, another reported, ‘I describe the brain/body has having a 'battery' just like a car…Post stroke the battery can be less full to start with, can be used up more quickly than usual and can take longer to recharge and not always fully’ [PT08].

Common

Pervasiveness was highlighted as a key issue; respondents typically used the terms ‘common’, ‘very common’ and ‘extremely common’ to describe PSF, often to start their response. Efforts to quantify this frequency were mixed; one answer asserted that PSF ‘affects nearly all stroke survivors’ [OT55], and another that ‘[PSF] affects a large number of patients, approx.. 25% [are] experiencing severe fatigue with a further 25% experiencing moderate fatigue’ [PT47]. Another felt that, ‘Following stroke approx. 75% of patients experience fatigue as a symptom’ [OT25].

Variable

Respondents emphasised the complex and variable nature of PSF as a condition, describing it as having several components or affecting multiple aspects of a patients’ life. Respondents attributed PSF to ‘a mix of physical and emotional factors’ [OT03], or provided more detailed causative processes, such as ‘hormones, neurotransmitters and cognitive load…exacerbated by secondary factors such as diet, sleep, medication’ [OT28]. The impact of PSF was also described as ‘holistic’, with multiple categories (‘physical and cognitive’) or specific aspects of impact (‘adversely effects patients sleep, appetite, motivation [sic]’ [PT25]).

Furthermore, respondents described the manifestation of PSF as particularly pernicious. Several reported that the fatigue experienced by stroke survivors was disproportionate to the cerebrovascular accident that had occurred, saying, ‘[PSF] has the highest impact in the least neurologically/physically impaired stroke patients’ [PT16]. One respondent described patients as only experiencing PSF when ‘they start trying to get back to everyday activities’ [OT56], and several indicated that fatigue affected patients’ ability to communicate with their family.

A Medical Condition: Legitimisation

Medicalisation of Symptoms

Responses emphasised the medical nature, and thus legitimacy, of PSF as a condition. PSF was described as a ‘condition’ or ‘symptom’ of stroke, from which patients were ‘suffering’. Some respondents explicitly differentiated PSF from tiredness, writing that PSF was ‘completely different to “normal” tiredness’ [OT11] or ‘not the same as being tired’ [OT32, PT18]. Similarly medicalising were efforts to quantify the fatigue, with respondents employing phrases such as ‘it can be measured, monitored, and energy conservation strategies applied’ [OT22].

Scientific language was used to support these assertions; participants attributed PSF to processes of damage and healing in the brain. Neurological explanations given for PSF included, ‘the brain reorganising connections’ [OT24], ‘[PSF happens] as neuroplasticity occurs’ [PT26], and PSF being ‘caused by the effect of stroke on hormones, neurotransmitters and cognitive load’ [OT28]. One respondent attributed fatigue ‘in-part to impairment of the regulatory systems in the brain - disruption to the network connections’ [OT54].

Applying a framework

In the absence of an existing formal classification framework, respondents offered a variety of systematic approaches to organise PSF into a number of constituent causes or effects. These included classifying fatigue into ‘peripheral’ vs. ‘central’, and ‘primary’ vs. ‘secondary’. This is typified by the following response: ‘there is usually a primary (i.e. central, or disease-specific) mechanism and a secondary (loss of fitness/function, mood/sleep related etc) mechanism at work’ [OT64].

Different Clinical Approaches

There was variation in understanding between therapists, which was both explicitly identified by respondents acknowledging differences and implicitly conveyed by variation between responses.

Several respondents highlighted the different approaches within their multi-disciplinary teams (MDT). One therapist wrote, ‘The doctors sometimes prescribe the patients modafinil … patients are often reviewed by the psychologist and the fatigue can be identified but I think there is a universal lack of knowing the best way to treat these patients’ [PT24]. A community physiotherapist highlighted this difficulty more explicitly, writing, ‘I do sometimes feel that OT & PT can give slightly conflicting messages. I appreciate that pacing is important, but sometimes [phrasing] can be very vague and misinterpreted...I often explain this …the OTs tend to be much more likely to encourage patients not to over do things [sic]… it can be a very tricky balancing act’ [PT33]. Another community-based physiotherapist asserted that, ‘[There are] different approaches in each discipline. OT[s] have most knowledge on fatigue management. Nursing and psychiatrists have the least knowledge and skill set to [manage] fatigue’ [PT48].

In addition to the acknowledgement of divergent opinions between health practitioners, there were substantial differences in the terminology used to define PSF. Respondents presented definitions that directly contradicted their peers. Key points of difference were whether PSF was termed ‘fatigue’ or ‘tiredness’ in responses, whether fatigue was related to activity undertaken, and what its prognosis was.

Tiredness or fatigue?

The majority of respondents distinguished between the concept of ‘tiredness’ and fatigue’, or defined fatigue as a particularly intense variant of tiredness (‘tiredness like no other’), as previously discussed. That these comments typically occurred at the start of the response suggests that this distinction was considered important. Other respondents used the terms ‘tiredness’ and ‘fatigue’ interchangeably, for example, ‘A tiredness that is not replenished by sleep and…can be physical, mental and emotional fatigue’ [OT63]. In other responses, it was unclear whether the terms were used synonymously (‘feelings of mild to extreme tiredness’ [PT32]). Some respondents appeared to define fatigue by its speed of onset, defining fatigue as, ‘feeling very easily tired’ [OT09] and ‘[to] get tired very quickly’ [PT54].

Role of activity?

Though there was consensus that fatigue had a serious effect on patients’ abilities to carry out activities of daily living (ADLs), there were inconsistencies in relating fatigue to activity. Some respondents wrote that PSF could ‘not be attributed to activity’ [OT03] and was ‘not related to the level of activity a person undertakes’ [OT20]. One felt PSF was ‘characterised by not being associated with recent levels of activity’ [OT31]. Conversely, others felt that the key to managing fatigue was to ‘understand...how activity affects these [energy] levels’ [OT22], and use ‘pacing’ as a strategy. Some responses were more equivocal, writing ‘impact is not necessarily related to activity levels’ [PT16] or ‘not always linked to activity completed’ [OT32]. Others indicated that fatigue was disproportionate to activity.

Respondents consistently referred to rest when defining PSF. Therapists felt rest or a lack thereof affected patients’ experience of PSF and should be considered when assessing for clinically significant fatigue. One stated ‘the best thing is to encourage the person to take complete rest...before doing anything else’ [OT12], whilst others agreed; the fatigue ‘reduces over time if adequate rest [is] taken [PT63]’ and that it ‘requires frequent rest periods’ [OT23]. Others mentioned rest but conversely were of the opinion that the condition ‘does not necessarily resolve following rest’ [OT06] and is ‘not eased by rest’ [OT31]. Others framed it as more of a diagnostic symptom, stating that PSF is ‘an absolute need to sleep and rest’ [PT55].

Timeframe?

Finally, there was a marked discrepancy between responses offering a timescale for PSF. Respondents suggested that PSF, ‘lasts…from weeks, to months to years or permanent’ [PT06], ‘usually improves 1 year to 2 years post stroke’ [PT53], and ‘may [last] for several months or even years’ [OT56]. Similar in style were the responses, ‘inability to participate in physio sessions longer than 15-20 mins’ [PT55] and ‘usually improves 1 year to 2 years post stroke’ [PT53]. Other responses addressed progression more vaguely, describing PSF as ‘ongoing’, or lessening ‘with time’.

Differences by professional background

We did not discern differences between how occupational therapists and physiotherapists communicated their understanding of PSF, though physiotherapists used medicalised terminology such as “symptom” and “condition” more frequently than occupational therapists. Length of clinical experience also appeared to have little impact on responses from therapists with between 5 and 20 years specialisation in stroke. Therapists with over 20 years’ experience alluded more frequently to the effect of PSF on ADLs and patient energy levels, often providing shorter and less holistic responses. Individuals with up to five years’ experience in the specialism demonstrated a notably medicalised approach.

We found that respondents in the acute setting typically used ‘medicalised’ terminology compared to those working in the community, among whom metaphor and patient expression were more common. Among the 25 respondents who identified themselves as working in acute care, answers were characterised by the medicalisation of PSF, and by the conceptualisation of fatigue as a symptom of vascular injury. There was an emphasis on the frequency of occurrence of PSF. Respondents were more likely to use statistics for emphasis. Respondents who identified themselves as working in acute care tended to use terminology more similar to a ‘dictionary definition’ of the condition. Conversely, those working in subacute (25) or primary care (3) tended to define stroke in terms of its lived impact, particularly with regard to rehabilitation and the effect of PSF on specific tasks, effort and rest. Subacute and primary care-based respondents were more likely to describe PSF in terms of impact on daily life and patient engagement with rehabilitation sessions, or in a holistic manner.

The majority of respondents identified themselves as working in a community setting (81). These responses were characterised by a focus on the clinical management, lived experience of PSF, and the use of metaphor. Though metaphor was a common feature of responses, it was particularly characteristic among community-based therapists. Several community-based respondents relayed patient descriptors of fatigue as part of their definition, such as ‘trying to “think through treacle”’ [OT18]. Almost all respondents who commented on variation in definitions and limitations to a common understanding of PSF, identified themselves as a community therapist. Though responses from this group displayed the most variation in definition of the key features of PSF, this may simply reflect the larger number of respondents from this setting.

DISCUSSION

Principal Findings

Respondents portrayed PSF as a highly debilitating condition which deserved greater attention. Medicalisation was viewed positively, as it reduced the stigma associated with this ‘invisible’ condition. Metaphor was used to convey the serious and debilitating nature of PSF. There was a lack of consistency regarding key features of the condition, in particular over terminology use (e.g. ‘tiredness’ or ‘fatigue’), treatment (e.g. the role of exercise), and prognosis. We found that respondents in the acute setting typically used ‘medicalised’ terminology compared to those working in the community, among whom metaphor and patient expression were more common.

Comparison to relevant literature

An overview of the fatigue literature

In 1971, McFarland stated that ‘fatigue’ is one of the most used and yet most poorly understood words in the English language [22]. Despite a sharp increase in published literature on fatigue over the last thirty years, and on PSF specifically in the past two decades, this appears to still hold true. When compared to other post-stroke and chronic conditions, research on PSF is still in its infancy; little research has targeted fatigue after stroke as the primary outcome, particularly regarding management and clinical understanding. Mechanistic work is ongoing, which will further strengthen therapist and patient understanding [15,16,23]. However, due to a lack of definitive answers, it is unsurprising that our respondents felt there was insufficient research addressing PSF.

The role of stroke survivor perspective

Though several qualitative studies have focused on stroke survivors’ understanding of PSF, previous literature has not examined healthcare professional understanding. Throughout the survey responses, metaphor and simple descriptive language were commonly used to emphasise the impact of PSF on stroke survivors, reflecting a central position of patient experience in clinical thinking around PSF. Several of the core characteristics identified by Eilertsen et al’s model of stroke survivors’ experiences of PSF [24] resonate with how therapists understood and defined the condition in our study. In both studies, individuals described PSF as an ‘invisible disability’ associated with stigmatisation, related fatigue to an ‘abnormal’ need to rest, and highlighted the lack of understanding and definition regarding PSF. Indeed, the authors felt that the ‘medicalisation’ identified in this dataset was employed to combat the evident stigma of PSF.

Inclusion in clinical guidelines

Collectively, the responses emphasised the importance of addressing PSF as a key post-stroke morbidity, and doing so in a holistic manner. Inclusion in clinical guidelines might improve recognition and guide practice. However, it is only recently starting to be included within prominent clinical guidelines [20,25,26]. As Eilertsen and colleagues argue, this lack of coverage may reflect the relative lack of high quality research in the field [24]. In order to legitimise PSF, therapists emphasise its medical nature, debilitative characteristics, and direct causative relationship with stroke. As Young et al. have demonstrated, medical language increases perceived severity and condition representativeness, especially for less well-known conditions [27,28].

Legitimacy of PSF in the multidisciplinary team

The extent to which therapists legitimise a patient’s symptoms can play a significant role in how the individual understands and navigates their condition. This is reflected often in fatigue literature; patients with rheumatoid arthritis report fatigue as overwhelming, uncontrollable and ignored [29], and studies indicate that it rarely forms a treatment target. By contrast, a survey of cancer-specialist therapists found that all professional groups overestimated the effects of fatigue compared to patient reports [30], though this may have been affected by the low response rate and degree of specialisation of the respondents involved. How far therapists engage with PSF may vary within a team. It is interesting that the open ended question we used led to discussion of the tensions involved in managing PSF within an MDT, indicating that this may be a particularly pertinent issue.

Strengths and weaknesses

The use of an online survey allowed respondents to participate from far-reaching geographical locations and removes the influence of an interviewer on responses. Nevertheless, the open nature of the survey question may have resulted in different interpretations of the study question, and our descriptive data is hindered by the inability to question respondents further (31). Though the survey was targeted to specialised therapists and responses were submitted by a diverse demographic of healthcare practitioners, the response rate was low, at 8%. This could mean that responses were taken primarily by healthcare professionals with greater interest and knowledge of post-stroke fatigue. Conversely, we had a relatively large number of respondents for a qualitative study, so it is unlikely that we failed to capture important themes. Although PTs and OTs often lead fatigue management programmes, other members of the MDT were not invited to take part which may limit the generalisability of our findings to other healthcare professionals. Qualitative analysis enabled the comprehensive and in-depth analysis of each response, however this precludes any broader generalisations about clinical practice as a whole.

Clinical Implications

PSF has been reported as an unmet need that is often misunderstood [1,9]. Our findings suggest that part of the problem may be that therapists working with stroke survivors conceptualise, explain and manage post stroke fatigue in different ways. This finding helps explain some of the findings of qualitative studies carried out with stroke survivors and care givers [26]. By drawing on both perspectives, guidance could be developed to support therapists assessing and educating their patients on PSF at all stages of the clinical pathway. This task would be made easier by a strong evidence-based framework for describing and explaining PSF in clinical practice and if there was a single widely adopted definition of post stroke fatigue. Research into causes and management of post stroke fatigue remains a priority.

Acknowledgements: We are grateful to all survey respondents who took the time to participate in our research. Many thanks to Donna Malley for her guidance and clinical expertise at the inception of this project.

Author Contributions: KT and RM contributed to the initial design of the study. KT and CH conducted data analysis and theme creation. KT, JM, CH and RM contributed to manuscript writing and editing.

Funding: This study was funded by the Malati Kanbur Studentship fund kindly donated by Ravi Kanbur and Margaret Grieco to Lucy Cavendish College, constituent college of the University of Cambridge. JM is supported by an NIHR Senior Investigator award. Views expressed in this written publication are those of the authors and not necessarily those of the funders.

Competing interests: None declared.

Provenance and peer review: Not commissioned, externally peer reviewed.

Data sharing statement: No additional data are available.

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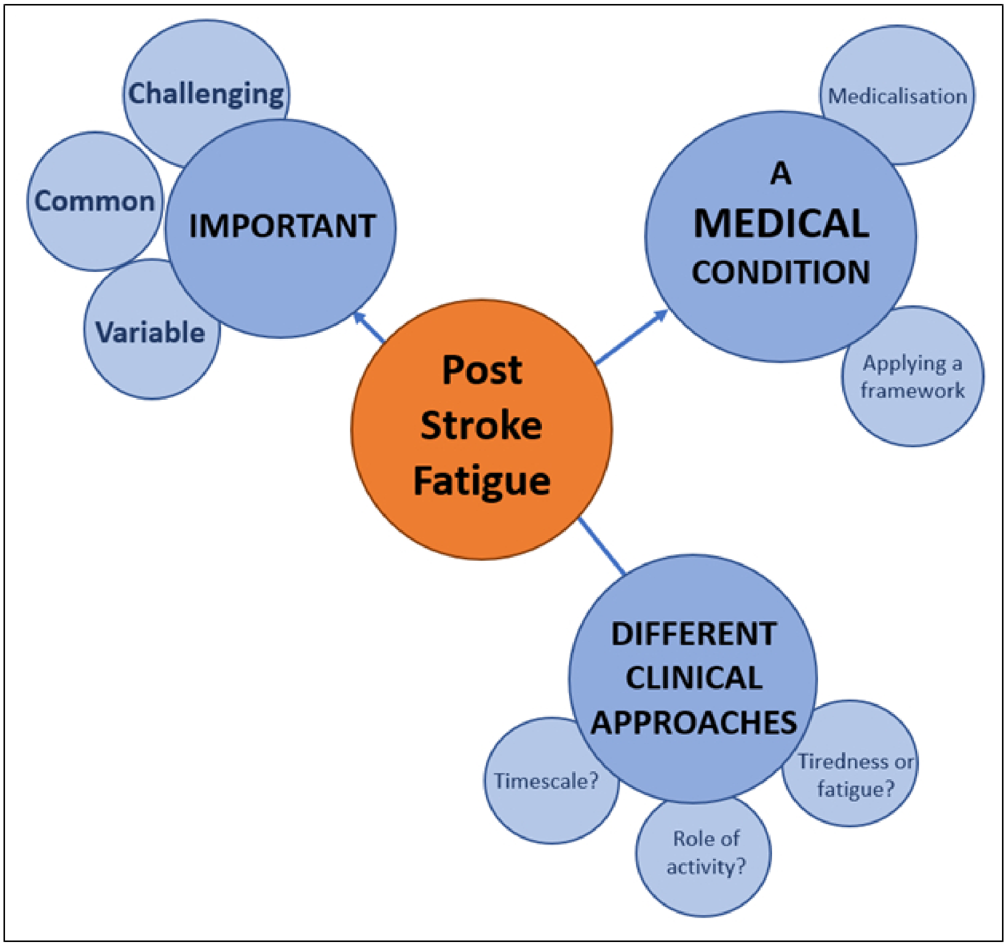

Figure 1: A visual representation of key themes arising in answer to the question 'How would you describe Post-Stroke Fatigue to another healthcare professional?'

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

		Reporting Item	Page Number
Title			
	#1	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	2
Abstract			
	#2	Summary of the 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	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	3
Purpose or research question	#4	Purpose of the study and specific objectives or questions	3

Methods

Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. 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.	4
Researcher characteristics and reflexivity	#6	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	11
Context	#7	Setting / site and salient contextual factors; rationale	4
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling	4

		saturation); rationale	
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	11
Data collection methods	#10	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	4
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	4
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	4, 5
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	4
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers	4

		involved in data analysis; usually references a specific paradigm or approach; rationale	
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	4
Results/findings			
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	5, 6
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	6-9
Discussion			
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	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 contributions(s) to scholarship in a discipline or field	10
Limitations	#19	Trustworthiness and limitations of findings	11
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	12

Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	12

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BMJ Open

Conceptualising Post-Stroke Fatigue: A Cross-Sectional Survey of UK based Physiotherapists and Occupational Therapists

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2019-033066.R2
Article Type:	Original research
Date Submitted by the Author:	12-Nov-2019
Complete List of Authors:	Thomas, Karen; University of Cambridge Department of Public Health and Primary Care, Public Health & Primary Care Hjalmarsson, Clarissa; University of Cambridge Department of Public Health and Primary Care, Public Health & Primary Care Mullis, Ricky; University of Cambridge, Department of Public Health and Primary Care Mant, Jonathan; University of Cambridge, General Practice and Primary Care Research Unit
Primary Subject Heading:	Qualitative research
Secondary Subject Heading:	Patient-centred medicine
Keywords:	Stroke < NEUROLOGY, fatigue, rehabilitation, QUALITATIVE RESEARCH, healthcare professional

Conceptualising Post-Stroke Fatigue: ***A Cross-Sectional Survey of UK based Physiotherapists and Occupational Therapists***

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ABSTRACT

With survival after stroke improving, more people are discharged into the community with multiple and persistent deficits. Fatigue is a common unmet need for stroke survivors, but there are no evidence-based guidelines for its assessment and management. This study explored how UK-based therapists conceptualise post-stroke fatigue in current practice.

Objective To describe current understanding of post-stroke fatigue (PSF) amongst physiotherapists and occupational therapists.

Design A cross-sectional online survey using Qualtrics software (a survey creation and analysis programme) was sent to therapists working with stroke survivors in 2019. Responses to the open ended question, 'How would you describe Post-Stroke Fatigue if approached by another healthcare professional?' were analysed thematically by two independent researchers.

Participants 137 survey respondents (71 physiotherapists, 66 occupational therapists) from a range of clinical settings (25 acute care, 25 sub-acute rehabilitation care, 3 primary care, 81 community care) with 7 months-36 years of experience working with stroke survivors completed the survey.

Results Respondents stated that post-stroke fatigue should be regarded as an important medical condition, because it is common and can be associated with severe symptoms. Symptoms were perceived to be highly variable and the syndrome was difficult to define objectively. It was felt to have both physical and cognitive components. A variety of different opinions were expressed with regard to causation, conceptualisation and best management.

Conclusion Therapists working with stroke survivors conceptualise and manage post stroke fatigue in different ways. Clinical practice is hampered by a lack of a widely adopted definition, and a small evidence base. Research into causes and treatments of post-stroke fatigue is a priority.

Key terms stroke, fatigue, rehabilitation, healthcare professional, qualitative approaches

Article Summary

Strengths and limitations of this study

- Strength: Survey design enables an efficient and nationally representative view of current clinical practice.
- Strength: Survey design removes the influence an interviewer may have on responses.
- Strength: The large number of respondents for a qualitative study means that it is unlikely that we failed to capture important themes.
- Limitation: Targeting only a specialist sub-population of therapists who routinely deal with PSF coupled with the 8% response rate may mean our findings were unrepresentative of broader clinical practice.
- Limitation: The open nature of the survey question may have resulted in different interpretations of the study question.

INTRODUCTION

Post-stroke fatigue (PSF) is a common symptom leading to unmet need for stroke survivors [1, 2]. It is a debilitating condition which adversely affects quality of life, social participation, return to work and mortality [3,4,5]. Despite this, PSF lacks an agreed definition, gold-standard outcome measure or an evidence-based therapeutic option [6,7,8]. Recent qualitative work contextualising PSF from a stroke survivor and care giver perspective highlighted that acknowledgement of PSF provided legitimacy, but healthcare professionals did not approach PSF in a consistent way [9]. In order to understand why this is, it is important to gain insight into the perspective of healthcare professionals on their understanding and management of the condition [10]. Knowledge of both patient and clinician perspective can inform current fatigue management pathways.

Previous work has sought to classify PSF into biological and psychological dimensions, and to identify primary and secondary aetiology [11,12]. In 1891, Mosso delineated two clear aspects of fatigue, drawing a distinction between the diminution of muscular force and the sensation of fatigue. He split this into physical fatigue, which is readily measurable, and a more elusive psychological element [13]. This classification continues to be used to explain a range of possible causative processes for fatigue [14]. Ongoing research in the field aims to understand the aetiology and mechanisms of PSF in greater depth, as definitive conclusions have not yet been reached [15,16,17]. Lynch and colleagues proposed the first case definition of PSF in 2007 and demonstrated its reliability and validity on stroke inpatients [18].

This is the first study to investigate how therapists regard PSF in current practice by posing the question “How would you describe Post-Stroke Fatigue to another healthcare professional?”.

METHOD

Patient and Public Involvement

Researcher KT visited a Cambridgeshire based stroke group to discuss their understanding and experience of post-stroke fatigue. Possible topics were informed by the current literature, including guidelines and recommendation documents [19,20]. The group gave feedback that improving understanding and management of post-stroke fatigue should be a priority.

Question Development

A ten question survey on the definition, assessment and management of post-stroke fatigue in clinical practice was developed by a multi-disciplinary group (physiotherapists, occupational therapists and a clinical psychologist working in Cambridgeshire community teams). This paper focuses on a single question relating to understanding of PSF which was created by lead author KT and then discussed and refined within the development group. The questions were piloted by three physiotherapists (PT) and one occupational therapist (OT), as a result of which alterations were made. The open ended question was revised following discussion at the questionnaire development group to specifically target healthcare professionals.

Participants

Physiotherapists who were members of the Association of Chartered Physiotherapists in Neurology (ACPIN) and occupational therapists who were members of Royal College of Occupational Therapy (RCOT) Specialist Section- Neurological Practice (RCOT-NSS) and who had registered an interest in participating in related research were invited to participate. To be eligible, participants were also required to have current registration as a healthcare professional, and to have worked with stroke survivors whilst in clinical practice within the United Kingdom.

Design

A cross-sectional survey [supplementary file] was created and answered electronically using Qualtrics software, an online survey creation and analysis site licensed to the University of Cambridge (https://eu.qualtrics.com).

Questionnaire Distribution

The research lead from each national organisation (ACPIN and RCOT-NSS) distributed an initial invitation email to members who had expressed an interest in participating in stroke-related research. Within the email was a participant invitation including a link to the Qualtrics platform which provided a participant information sheet and a consent form. Respondents entered their answers directly on to the Qualtrics online platform. After two weeks, a reminder email was sent to individuals who had not completed the survey. The survey remained live for one month following the reminder.

Data analysis

Submitted survey responses were collated on the Qualtrics platform (https://www.qualtrics.com/blog/citing-qualtrics/) and downloaded using https secure protocol to the Secure Data Hosting Service at the University of Cambridge. These data were then anonymised and loaded into Microsoft Excel. Responses to question 5 "How would you describe Post-Stroke Fatigue if approached by another healthcare professional?" were analysed thematically by two independent researchers KT and CH. KT and CH first familiarised themselves with the data set. Both researchers coded 5% of the data to ensure a consistent coding strategy, then 40% of posts were randomly selected and coded by researcher CH while the remaining 60% were coded by KT. After all data had been coded, both researchers met and discussed the allocated codes, re-coding the data until unanimous agreement was reached. Codes were then grouped into sub-themes which were organised to create a thematic model. All responses were checked by both researchers to ensure all data fitted into the model. Descriptive statistics were used to analyse respondent characteristics and decipher frequencies within the data set.

Ethical approval

All documentation was approved by Cambridge University Psychology Ethics Committee (PRE.2017.092). We used the SRQR checklist when writing our report [21].

RESULTS

Participant Characteristics

700 occupational therapists and 800 physiotherapists were sent a study invitation email of whom 137 completed the survey. Responses varied considerably in length from 2 to 148 words. with a median of 49 words. Occupational therapists and physiotherapists responded in similar numbers (66

occupational therapists, 71 physiotherapists). Respondents had experience working in a variety of settings with stroke survivors: acute care (25 respondents); sub-acute rehabilitation care (24); community care (85); and primary care (3). The duration of specialism individuals had in stroke ranged from 7 months to 33 years [Table 1].

Participant respondents	Number
Profession	
Occupational therapist	66
Physiotherapist	71
Clinical setting	
Acute	25
Sub-Acute	24
Community	85
Primary Care	3
Duration of specialism	
< 1 year	4
1-5 years	29
6-10 years	41
11-15 years	17
16-20 years	19
21 + years	27

Table 1: Respondent characteristics by profession, clinical setting and duration of specialism

Themes

Overview

The survey question, ‘How would you describe Post-Stroke Fatigue if approached by another healthcare professional?’ generated a range of responses which were grouped into three broad themes shown below in Figure 1: the importance of PSF; its legitimacy as a medical condition; the variety of ways in which healthcare professionals approach it.

[Figure submitted seperately to main text]

Figure 1: A visual representation of key themes arising in answer to the question ‘How would you describe Post-Stroke Fatigue to another healthcare professional?’

Important: *Challenging, Common and Variable nature*

A common response was that PSF was debilitating and deeply pervasive among stroke survivors. Respondents described PSF by using the descriptor ‘overwhelming’, and various other words to that effect. The term ‘debilitating’, and descriptors such as ‘all-consuming’, ‘extreme’, and ‘tiredness like no other’ were typical.

Challenging

Descriptive language was a marked feature of the responses, as therapists responded creatively to the challenge of explaining the difficulties of PSF to colleagues. Further, respondents highlighted the challenging nature of PSF and the effects this had on their patients. Answers stated, ‘patients[sic] often feel like they are ‘thinking through mud’ [OT09] and ‘pulling heavy boots on’ [OT32]. Others emphasised the traumatic nature of PSF, describing it as ‘hitting a brick wall’ [OT62], and ‘like your brain had been in a washing machine on a spin cycle' [OT47]. Medicalised metaphors were also used, one of which likened the fatigue to 'sensory overload' [PT04].

Extended analogies were employed to convey the experience of living with PSF. One response suggested, 'I sometimes describe it as a bruise on the brain, and if you imagine a bruise on your ankle, you can see it's[sic] sore and stiff and you can't walk much before needing to rest' [OT27]. One respondent directly referred to using 'the spoons analogy'[OT58]. Coined by Christine Miserandino in 2003 to describe her experience of lupus, 'Spoon Theory' explains fatigue associated with chronic medical conditions by referring to having only limited number of 'spoons' of energy that the patient can 'spend' during the day (https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/). In a similar manner, another reported, 'I describe the brain/body has having a 'battery' just like a car…Post stroke the battery can be less full to start with, can be used up more quickly than usual and can take longer to recharge and not always fully' [PT08].

Common

Pervasiveness was highlighted as a key issue; respondents typically used the terms 'common', 'very common' and 'extremely common' to describe PSF, often to start their response. Efforts to quantify this frequency were mixed; one answer asserted that PSF 'affects nearly all stroke survivors' [OT55], and another that '[PSF] affects a large number of patients, approx.. 25% [are] experiencing severe fatigue with a further 25% experiencing moderate fatigue' [PT47]. Another felt that, 'Following stroke approx. 75% of patients experience fatigue as a symptom' [OT25].

Variable

Respondents emphasised the complex and variable nature of PSF as a condition, describing it as having several components or affecting multiple aspects of a patients' life. Respondents attributed PSF to 'a mix of physical and emotional factors' [OT03], or provided more detailed causative processes, such as 'hormones, neurotransmitters and cognitive load…exacerbated by secondary factors such as diet, sleep, medication' [OT28]. The impact of PSF was also described as 'holistic', with multiple categories ('physical and cognitive') or specific aspects of impact ('adversely effects patients sleep, appetite, motivation [sic]' [PT25]).

Furthermore, respondents described the manifestation of PSF as particularly pernicious. Several reported that the fatigue experienced by stroke survivors was disproportionate to the cerebrovascular accident that had occurred, saying, '[PSF] has the highest impact in the least neurologically/physically impaired stroke patients' [PT16]. One respondent described patients as only experiencing PSF when 'they start trying to get back to everyday activities' [OT56], and several indicated that fatigue affected patients' ability to communicate with their family.

A Medical Condition: Legitimisation

Medicalisation of Symptoms

Responses emphasised the medical nature, and thus legitimacy, of PSF as a condition. PSF was described as a 'condition' or 'symptom' of stroke, from which patients were 'suffering'. Some respondents explicitly differentiated PSF from tiredness, writing that PSF was 'completely different to "normal" tiredness' [OT11] or 'not the same as being tired' [OT32, PT18]. Similarly medicalising were efforts to quantify the fatigue, with respondents employing phrases such as 'it can be measured, monitored, and energy conservation strategies applied' [OT22].

Scientific language was used to support these assertions; participants attributed PSF to processes of damage and healing in the brain. Neurological explanations given for PSF included, 'the brain reorganising connections' [OT24], '[PSF happens] as neuroplasticity occurs' [PT26], and PSF being 'caused by the effect of stroke on hormones, neurotransmitters and cognitive load' [OT28]. One respondent attributed fatigue 'in-part to impairment of the regulatory systems in the brain - disruption to the network connections' [OT54].

Applying a framework

In the absence of an existing formal classification framework, respondents offered a variety of systematic approaches to organise PSF into a number of constituent causes or effects. These included classifying fatigue into 'peripheral' vs. 'central', and 'primary' vs. 'secondary'. This is typified by the following response: 'there is usually a primary (i.e. central, or disease-specific) mechanism and a secondary (loss of fitness/function, mood/sleep related etc) mechanism at work' [OT64].

Different Clinical Approaches

There was variation in understanding between therapists, which was both explicitly identified by respondents acknowledging differences and implicitly conveyed by variation between responses.

Several respondents highlighted the different approaches within their multi-disciplinary teams (MDT). One therapist wrote, 'The doctors sometimes prescribe the patients modafinil … patients are often reviewed by the psychologist and the fatigue can be identified but I think there is a universal lack of knowing the best way to treat these patients' [PT24]. A community physiotherapist highlighted this difficulty more explicitly, writing, 'I do sometimes feel that OT & PT can give slightly conflicting messages. I appreciate that pacing is important, but sometimes [phrasing] can be very vague and misinterpreted...I often explain this …the OTs tend to be much more likely to encourage patients not to over do things [sic]… it can be a very tricky balancing act' [PT33]. Another community-based physiotherapist asserted that, '[There are] different approaches in each discipline. OT[s] have most knowledge on fatigue management. Nursing and psychiatrists have the least knowledge and skill set to [manage] fatigue' [PT48].

In addition to the acknowledgement of divergent opinions between health practitioners, there were substantial differences in the terminology used to define PSF. Respondents presented definitions that directly contradicted their peers. Key points of difference were whether PSF was termed 'fatigue' or 'tiredness' in responses, whether fatigue was related to activity undertaken, and what its prognosis was.

Tiredness or fatigue?

The majority of respondents distinguished between the concept of 'tiredness' and fatigue', or defined fatigue as a particularly intense variant of tiredness ('tiredness like no other'), as previously discussed. That these comments typically occurred at the start of the response suggests that this distinction was considered important. Other respondents used the terms 'tiredness' and 'fatigue' interchangeably, for example, 'A tiredness that is not replenished by sleep and…can be physical, mental and emotional fatigue' [OT63]. In other responses, it was unclear whether the terms were used synonymously ('feelings of mild to extreme tiredness' [PT32]). Some respondents appeared to define fatigue by its speed of onset, defining fatigue as, 'feeling very easily tired' [OT09] and '[to] get tired very quickly' [PT54].

Role of activity?

Though there was consensus that fatigue had a serious effect on patients' abilities to carry out activities of daily living (ADLs), there were inconsistencies in relating fatigue to activity. Some respondents wrote that PSF could 'not be attributed to activity' [OT03] and was 'not related to the level of activity a person undertakes' [OT20]. One felt PSF was 'characterised by not being associated with recent levels of activity' [OT31]. Conversely, others felt that the key to managing fatigue was to 'understand...how activity affects these [energy] levels' [OT22], and use 'pacing' as a strategy. Some responses were more equivocal, writing 'impact is not necessarily related to activity levels' [PT16] or 'not always linked to activity completed' [OT32]. Others indicated that fatigue was disproportionate to activity.

Respondents consistently referred to rest when defining PSF. Therapists felt rest or a lack thereof affected patients' experience of PSF and should be considered when assessing for clinically significant fatigue. One stated 'the best thing is to encourage the person to take complete rest...before doing anything else' [OT12], whilst others agreed; the fatigue 'reduces over time if adequate rest [is] taken [PT63]' and that it 'requires frequent rest periods' [OT23]. Others mentioned rest but conversely were of the opinion that the condition 'does not necessarily resolve following rest' [OT06] and is 'not eased by rest' [OT31]. Others framed it as more of a diagnostic symptom, stating that PSF is 'an absolute need to sleep and rest' [PT55].

Timeframe?

Finally, there was a marked discrepancy between responses offering a timescale for PSF. Respondents suggested that PSF, 'lasts…from weeks, to months to years or permanent' [PT06], 'usually improves 1 year to 2 years post stroke' [PT53], and 'may [last] for several months or even years' [OT56]. Similar in style were the responses, 'inability to participate in physio sessions longer than 15-20 mins' [PT55] and 'usually improves 1 year to 2 years post stroke' [PT53]. Other responses addressed progression more vaguely, describing PSF as 'ongoing', or lessening 'with time'.

Differences by professional background

We did not discern differences between how occupational therapists and physiotherapists communicated their understanding of PSF, though physiotherapists used medicalised terminology such as "symptom" and "condition" more frequently than occupational therapists. Length of clinical experience also appeared to have little impact on responses from therapists with between 5 and 20 years specialisation in stroke. Therapists with over 20 years' experience alluded more frequently to the effect of PSF on ADLs and patient energy levels, often providing shorter and less holistic responses. Individuals with up to five years' experience in the specialism demonstrated a notably medicalised approach.

We found that respondents in the acute setting typically used 'medicalised' terminology compared to those working in the community, among whom metaphor and patient expression were more common. Among the 25 respondents who identified themselves as working in acute care, answers were characterised by the medicalisation of PSF, and by the conceptualisation of fatigue as a symptom of vascular injury. There was an emphasis on the frequency of occurrence of PSF. Respondents were more likely to use statistics for emphasis. Respondents who identified themselves as working in acute care tended to use terminology more similar to a 'dictionary definition' of the condition. Conversely, those working in subacute (25) or primary care (3) tended to define stroke in terms of its lived impact, particularly with regard to rehabilitation and the effect of PSF on specific tasks, effort and rest. Subacute and primary care-based respondents were more likely to describe PSF in terms of impact on daily life and patient engagement with rehabilitation sessions, or in a holistic manner.

The majority of respondents identified themselves as working in a community setting (81). These responses were characterised by a focus on the clinical management, lived experience of PSF, and the use of metaphor. Though metaphor was a common feature of responses, it was particularly characteristic among community-based therapists. Several community-based respondents relayed patient descriptors of fatigue as part of their definition, such as 'trying to "think through treacle"' [OT18]. Almost all respondents who commented on variation in definitions and limitations to a common understanding of PSF, identified themselves as a community therapist. Though responses from this group displayed the most variation in definition of the key features of PSF, this may simply reflect the larger number of respondents from this setting.

DISCUSSION

Principal Findings

Respondents portrayed PSF as a highly debilitating condition which deserved greater attention. Medicalisation was viewed positively, as it reduced the stigma associated with this ‘invisible’ condition. Metaphor was used to convey the serious and debilitating nature of PSF. There was a lack of consistency regarding key features of the condition, in particular over terminology use (e.g. ‘tiredness’ or ‘fatigue’), treatment (e.g. the role of exercise), and prognosis. We found that respondents in the acute setting typically used ‘medicalised’ terminology compared to those working in the community, among whom metaphor and patient expression were more common.

Comparison to relevant literature

An overview of the fatigue literature

In 1971, McFarland stated that ‘fatigue’ is one of the most used and yet most poorly understood words in the English language [22]. Despite a sharp increase in published literature on fatigue over the last thirty years, and on PSF specifically in the past two decades, this appears to still hold true. When compared to other post-stroke and chronic conditions, research on PSF is still in its infancy; little research has targeted fatigue after stroke as the primary outcome, particularly regarding management and clinical understanding. Mechanistic work is ongoing, which will further strengthen therapist and patient understanding [15,16,23]. However, due to a lack of definitive answers, it is unsurprising that our respondents felt there was insufficient research addressing PSF.

The role of stroke survivor perspective

Though several qualitative studies have focused on stroke survivors’ understanding of PSF, previous literature has not examined healthcare professional understanding. Throughout the survey responses, metaphor and simple descriptive language were commonly used to emphasise the impact of PSF on stroke survivors, reflecting a central position of patient experience in clinical thinking around PSF. Several of the core characteristics identified by Eilertsen et al’s model of stroke survivors’ experiences of PSF [24] resonate with how therapists understood and defined the condition in our study. In both studies, individuals described PSF as an ‘invisible disability’ associated with stigmatisation, related fatigue to an ‘abnormal’ need to rest, and highlighted the lack of understanding and definition regarding PSF. Indeed, the authors felt that the ‘medicalisation’ identified in this dataset was employed to combat the evident stigma of PSF.

Inclusion in clinical guidelines

Collectively, the responses emphasised the importance of addressing PSF as a key post-stroke morbidity, and doing so in a holistic manner. Inclusion in clinical guidelines might improve recognition and guide practice. However, it is only recently starting to be included within prominent clinical guidelines [20,25,26]. As Eilertsen and colleagues argue, this lack of coverage may reflect the relative lack of high quality research in the field [24]. In order to legitimise PSF, therapists emphasise its medical nature, debilitative characteristics, and direct causative relationship with stroke. As Young et al. have demonstrated, medical language increases perceived severity and condition representativeness, especially for less well-known conditions [27,28].

Legitimacy of PSF in the multidisciplinary team

The extent to which therapists legitimise a patient’s symptoms can play a significant role in how the individual understands and navigates their condition. This is reflected often in fatigue literature; patients with rheumatoid arthritis report fatigue as overwhelming, uncontrollable and ignored [29], and studies indicate that it rarely forms a treatment target. By contrast, a survey of cancer-specialist therapists found that all professional groups overestimated the effects of fatigue compared to patient reports [30], though this may have been affected by the low response rate and degree of specialisation of the respondents involved. How far therapists engage with PSF may vary within a team. It is interesting that the open ended question we used led to discussion of the tensions involved in managing PSF within an MDT, indicating that this may be a particularly pertinent issue.

Strengths and weaknesses

The use of an online survey allowed respondents to participate from far-reaching geographical locations and removes the influence of an interviewer on responses. Nevertheless, the open nature of the survey question may have resulted in different interpretations of the study question, and our descriptive data is hindered by the inability to question respondents further [31]. Though the survey was targeted to specialised therapists and responses were submitted by a diverse demographic of healthcare practitioners, the response rate was low, at 8%. This could mean that responses were taken primarily by healthcare professionals with greater interest and knowledge of post-stroke fatigue. Conversely, we had a relatively large number of respondents for a qualitative study, so it is unlikely that we failed to capture important themes. Although PTs and OTs often lead fatigue management programmes, other members of the MDT were not invited to take part which may limit the generalisability of our findings to other healthcare professionals. Qualitative analysis enabled the comprehensive and in-depth analysis of each response, however this precludes any broader generalisations about clinical practice as a whole.

Clinical Implications

PSF has been reported as an unmet need that is often misunderstood [1,9]. Our findings suggest that part of the problem may be that therapists working with stroke survivors conceptualise, explain and manage post stroke fatigue in different ways. This finding helps explain some of the findings of qualitative studies carried out with stroke survivors and care givers [26]. By drawing on both perspectives, guidance could be developed to support therapists assessing and educating their patients on PSF at all stages of the clinical pathway. This task would be made easier by a strong evidence-based framework for describing and explaining PSF in clinical practice and if there was a single widely adopted definition of post stroke fatigue. Research into causes and management of post stroke fatigue remains a priority.

Acknowledgements: We are grateful to all survey respondents who took the time to participate in our research. Many thanks to Donna Malley for her guidance and clinical expertise at the inception of this project.

Author Contributions: KT and RM contributed to the initial design of the study. KT and CH conducted data analysis and theme creation. KT, JM, CH and RM contributed to manuscript writing and editing.

Funding: This study was funded by the Malati Kanbur Studentship fund kindly donated by Ravi Kanbur and Margaret Grieco to Lucy Cavendish College, constituent college of the University of Cambridge. JM is supported by an NIHR Senior Investigator award. Views expressed in this written publication are those of the authors and not necessarily those of the funders.

Competing interests: None declared.

Provenance and peer review: Not commissioned, externally peer reviewed.

Data sharing statement: No additional data are available.

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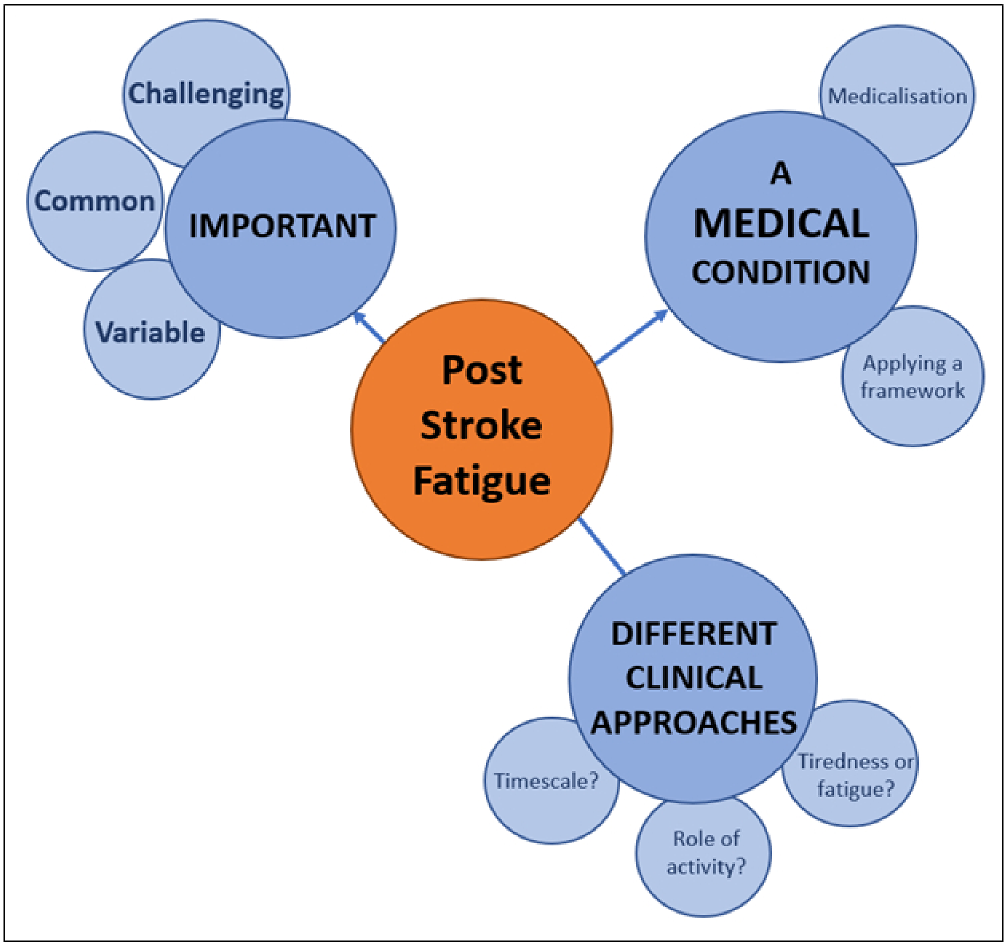

Figure 1: A visual representation of key themes arising in answer to the question ‘How would you describe Post-Stroke Fatigue to another healthcare professional?’

Survey Design

To see survey please follow this link: http://cambridge.eu.qualtrics.com/jfe/form/SV_1F9dri1rY2UinVX

Block 1 – Front Page

Understanding Post-Stroke Fatigue: A Clinical Perspective

Thank you for taking the time to read the invitation email and following the link to find out more. Before progressing, please take the time to look at the Participant Information Sheet .

The next page comprises a consent form required to proceed to the survey. As stated previously, you can withdraw from the survey at any point by exiting the screen or can choose to not respond to any questions you feel unable to answer.

Thank you for your time and helping progress this field of research with your clinical expertise.

Karen Thomas
(Chief Investigator)
University of Cambridge

Block 2 – Consent Form

Consent Form

This information is being collected as part of a PhD research project by the Primary Care Unit, part of the University of Cambridge. The information which you supply and that which may be collected as part of the research project will be entered into a database only accessible by authorised personnel. The information will be retained by the University of Cambridge, only used for research, statistical and audit purposes. By supplying this information, you are consenting to the University storing your information for the purposes stated above. The information will be processed by the University of Cambridge in accordance with the provisions of the Data Protection Act 1998.

1. I have read the attached information sheet and the study has been explained to my satisfaction.	[Tick Box]
2. I am willing to take part in the survey and understand that I am free to withdraw at any time.	[Tick Box]
3. I understand that I can withdraw my data up to 2 weeks following completion of the survey.	[Tick Box]
4. I confirm that I am a practicing occupational or physical therapist and have (in the past five years) or am currently working with a stroke survivor population.	[Tick Box]

5. I give permission for the study investigator to have access to my data and understand that any information will be kept strictly confidential.	[Tick Box]
6. I understand that my digital and questionnaire data will be stored for a minimum of 5 years in accordance with University of Cambridge policies on password protected systems accessible only to research personnel associated with this study. I agree to this.	[Tick Box]
7. I agree to participate in this study.	[Tick Box]
8. I wish to receive the study results.	[Tick Box]

Please sign below using your mouse or touch pad.

[Electronic Signature Box]

This must be fully and accurately completed to continue onwards to the main survey block.

Block 3 – Main Survey

1. **What profession do you practice?**
   [Multiple choice answer – only able to select one option]

   Physiotherapy

   Occupational Therapy

2. **What setting do you work in?**
   [Multiple choice question – only able to select one option]

○ Acute care

○ Sub-acute rehabilitation care

○ Community care

○ Primary care

3. **How long have you been working with stroke survivors?**
   [Single line short answer question]

4. **Briefly, what experience do you have working with stroke survivors experiencing fatigue?**
   [Multiple line short answer question]

5. **How would you describe post-stroke fatigue if approached by another healthcare professional?**
   [Multiple line short answer question]

6. **Please list the questions which you would ask the stroke survivor in a subjective assessment targeting post-stroke fatigue?**
   [Essay text box long answer question]

7. **When assessing a patient you believe may be experiencing post-stroke fatigue, would you use a fatigue specific scale? If yes, which scale(s) would you use?**
   [Multiple choice question – able to select multiple options]

☐ I would not use a scale

☐ Fatigue Severity Scale (FSS)

☐ Fatigue Assessment Scale (FAS)

☐ Neurological Fatigue Index for Stroke (NFI-Stroke)

☐ Faces Rating Scale (NRS-FRS)

☐ Other [text box entry to enable clarification]

8. **Why do you assess stroke survivors experiencing post-stroke fatigue in this way?**
   [Multiple line short answer question]

9. **What treatment techniques have you employed in helping stroke survivors manage their fatigue and which were the most useful?**
[Multiple line short answer question]

10. Do you have any further comments to make regarding assessment and management of post-stroke fatigue?

[Multiple line short answer question]

Would you be interested in:

[Multiple choice question – able to select multiple options]

☐ Being contacted for further research in the form of small focus groups with other healthcare professionals?

☐ Receiving a regular newsletter of advances in the field of Post-Stroke Fatigue?

If yes to either of the above, please provide your email address:
[Single line short answer question]

Thankyou message following submission of answers and completion of Block 3- Main Survey.

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

		Reporting Item	Page Number
Title			
	#1	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	2
Abstract			
	#2	Summary of the 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	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	3
Purpose or research question	#4	Purpose of the study and specific objectives or questions	3

Methods

Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. 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.	4
Researcher characteristics and reflexivity	#6	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	11
Context	#7	Setting / site and salient contextual factors; rationale	4
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling	4

		saturation); rationale	
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	11
Data collection methods	#10	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	4
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	4
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	4, 5
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	4
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers	4

		involved in data analysis; usually references a specific paradigm or approach; rationale	
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	4
Results/findings			
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	5, 6
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	6-9
Discussion			
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	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 contributions(s) to scholarship in a discipline or field	10
Limitations	#19	Trustworthiness and limitations of findings	11
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	12

Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	12

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