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Constructs of Post-Stroke Fatigue: ***Insights from stroke survivors and their carers via thematic analysis of an online discussion forum.***

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Objective To understand post-stroke fatigue from the perspective of stroke survivors and their care-givers expressed in an online discussion forum.

Design. The search terms 'tiredness', 'fatigue', 'tired', 'weary' and 'weariness' were used to identify relevant posts. Thematic analysis was performed by two independent researchers who coded all forum posts and then together identified pertinent themes.

Posts were coded in relation to two research questions; (1) How is post-stroke fatigue described? (2) What coping strategies are suggested to target post-stroke fatigue? Each identified theme was then summarised by a lead quotation in forum users' own words.

Setting United Kingdom based web forum hosted by Stroke Association; TalkStroke. Archives from 2004-2011 were accessed.

Participants 65 stroke survivors and care-givers (61% female, 39% male, mean age 54) contributed to 89 relevant posts which included a relevant search term. This included 38 stroke survivors, 23 individuals in a family or carer role and 4 others who were unidentified.

Results Six themes were generated: 1. Medicalisation of Post-Stroke Fatigue: "a classic post-stroke symptom" , 2. A Tiredness Unique to Stroke: "a legacy of stroke", 3. Normalisation and Acceptance of Post-Stroke Fatigue: "part and parcel of stroke", 4. Fighting the Fatigue: "an unwelcome guest", 5. Survivors' and Care Givers' Biological Explanations: "the brain healing", 6. Coping Mechanisms: "pace yourself". Forum users also repeatedly commented that post-stroke fatigue was "not understood by the profession".

Conclusion This is the first study to employ data from an online forum to characterise post-stroke fatigue. Our data is considered naturalistic owing to the absence of a researcher guiding the discussion, and thus generates useful insights for healthcare professionals. Further research is required to translate this understanding of the patient and carer perspective into ways to improve management of post-stroke fatigue.

Key terms stroke, fatigue, rehabilitation, chronic illness, qualitative approaches

Article Summary

Strengths and limitations of this study

- **Strengths**

Analysis of data from an online community enables naturalistic data collection without the potential bias associated with research interviews.

This method of data collection employs direct analysis of posts written by stroke survivors and carers in the context of the forum, rather than in an "unnatural" research setting.

Using an online forum data set in this manner can complement traditional data collection techniques such as research interviews for qualitative research.

- **Limitations**

Forum users may not be typical of the stroke community – they tend to be younger and have less severe strokes (though this can be off-set by caregivers' contributions).

Introduction

Every year in the UK, 110,000 individuals experience a stroke[1]. Prevalence of fatigue after stroke has been reported to be as high as 70%, yet there is currently minimal evidence on which to base an effective management strategy[2-4]. Amongst stroke survivors living in the community with fatigue, 43% report this need as unmet[5]. Fatigue after stroke adversely affects survivors' quality of life, social participation, return to work and survival[2,6,7].

Better understanding of post-stroke fatigue would enable healthcare professionals to identify patients with clinically significant fatigue who may benefit from further investigation and support[6]. However, defining post-stroke fatigue is challenging due to its complex biopsychosocial elements and its 'inherent subjectivity'[8,9]. This may be mitigated by incorporating an improved understanding of survivors' perceptions into a working definition of post-stroke fatigue for health care professionals[10].

Post-stroke fatigue varies in its clinical presentation and the mechanisms that underlie it are poorly understood[11]. Some patients suffer from post-stroke fatigue for many years more than others with equivalent neurological damage[11]. There is some evidence to suggest that the experience of post-stroke fatigue is associated with factors such as anxiety, reduced quality of life and physical activity[12]. It has been proposed that post-stroke fatigue should be considered independently from other associated conditions such as depression, pain and sleep disorders[13]. Although post-stroke fatigue is highly subjective in nature, there is limited published research exploring the patient narrative[11]. A better understanding of the patient perspective within a biopsychosocial approach might facilitate a better understanding of the condition[14, 15].

Online forums provide a rich source of data from which subjective experiences of the issues pertinent to the population in question may be collected[16]. Online communities increasingly provide a platform for patients and care-givers to seek information, support, and discuss their conditions[17]. The resulting data are generated from natural interactions between fellow forum users rather than from guided discussions with researchers[17]. As such, analysis of online communities can uncover additional material in comparison to traditional qualitative methodologies[16].

This study aimed to understand post-stroke fatigue by analysis of discussions in an online forum dedicated to stroke survivors and their care-givers. We asked two research questions: (1) How is post-stroke fatigue described? and (2) What coping strategies are suggested to target post-stroke fatigue?

Methods

Design

This study employed thematic analysis of posts relating to post-stroke fatigue (PSF) written by stroke survivors and care-givers on the archived Talkstroke Forum. The forum comprises 22,173 unique posts, 2583 usernames and is a UK-based online community hosted by the Stroke Association charity. We analysed forum posts including our search term "tiredness" and related terms "fatigue", "tired", "weary" and "weariness" from a total of 71 TalkStroke forum participants, written by stroke survivors and their care-givers between 2004-2011.

Ethics

The Stroke Association gave ADS access to the forum archives and permission for the data to be used for research purposes. Talkstroke data were stored and accessed through the University of Cambridge Clinical School Secure Data Hosting Service (SDHS). People signing up to Talkstroke agreed that their data were public upon registering for the forum. To protect the identity and intellectual property of forum participants, we report fragments of responses and paraphrase longer discussion points.

Data Selection

Two researchers KT and CG searched the forum archives for the following search terms: "tiredness", "tired", "fatigue", "weary" and "weariness". Repeated and irrelevant posts were removed, as agreed by KT and CG through use of two rounds of coding and discussion. Posts with only a cursory mention of tiredness/fatigue or fatigue in relation to depression, pain or sleep disorders were excluded, as they strayed from the focus on fatigue as a direct consequence of stroke. Posts written by individuals under the age of 18 or by a parent figure describing their child were also removed since the focus of this study was adult stroke. This gave a preliminary data set of 104 posts written by 71 forum users. These posts were again screened by KT and CG to assess their relevance to the research questions and discussed until unanimous agreement was reached regarding the final data set, which comprised 89 posts written by 65 individuals.

Data Analysis

After reading all posts in the final data set to ensure familiarisation with the content, two researchers (KT and CG) carried out inductive thematic analysis to generate and refine emerging issues, using methods described by Braun and Clarke[20]. Posts were coded in order to answer the two research questions, by identifying the defining characteristics of post-stroke fatigue and revealing coping strategies. The majority (65%) of posts were coded by the first author (KT). Coding was performed independently for 30% of posts by the second author (CG). 5% of posts were coded by both researchers to ensure a consistent, systematic coding style was being used. Coding was discussed until agreement was reached for all posts to identify all pertinent key themes. These codes were aggregated into broader themes. During this process, both researchers revisited all extracts to ensure the suggested themes incorporated all data entries and thus the six final themes truly represented the complete data set. The process for data selection and analysis is summarised in Figure 1.

[Attached as separate file]

Figure 1. Flowchart of process for data selection and analysis.

Results

Participant Characteristics

65 individuals wrote 89 posts in the TalkStroke forum which included the selected search terms. This included 38 stroke survivors, 23 individuals in a family or carer role and 4 others who were unidentified. 61% of survivors were female while 39% were male and median age was 54 (range 32 to 84) years of age. The above demographics specifically refer to stroke survivors either posting about their own experience or being referred to by a carer figure using the forum.

Themes

We identified six themes representing a wide variety of understanding and approaches to post-stroke fatigue by stroke survivors and care-givers alike. Following data familiarisation, using the 2 research questions, 62 initial codes were created and discussed to enable collation into the final six themes. KT and CG identified codes emerging from survivor and carer posts to check for differences and due to no clear variance identified, the final six themes were created encompassing both experiential viewpoints.

***Medicalisation of Post-Stroke Fatigue*: "A classic post stroke symptom"**

Forum participants employed language highly suggestive of medicalisation such as 'suffers with fatigue'. Yet there was also much discussion about long-term effects of stroke as 'not understood by the profession'. One individual reported attending two outpatient appointments following discharge from the stroke ward in which his fatigue was never addressed. This is at odds with the strongly held idea by many stroke survivors on the forum that 'tiredness is very much a part of stroke symptoms… a classic post-stroke symptom'.

***Tiredness like no other:* "A legacy of stroke"**

A number of forum users discussed the features of post-stroke fatigue itself. It was described as 'a fatigue like no other', and a 'neurological tiredness'. There were multiple references to the idea that 'stroke can and does cause fatigue', that fatigue is 'a feature of our affliction', and some took this further, characterising post-stroke fatigue as a distinct problem; 'a thing in itself, aside from chronic fatigue syndrome'. Further, fatigue was repeatedly expressed by forum users as a 'legacy of stroke' or a 'typical post-stroke legacy', encapsulating survivors' experiences of a long-lasting fatigue directly linked to the stroke.

***Acceptance and normalisation of Post-Stroke Fatigue*: "Part and parcel"**

Often, stroke survivors asked other forum users 'is this tiredness normal?', obtaining a plethora of affirmative responses. This can be summarised by the idea proposed by one participant that post-stroke fatigue 'is a guest you're stuck with, you've just got to learn to live with it', and that 'the feelings are normal and all stroke survivors can relate to the tiredness'. Along with the reassurance that 'tiredness (fatigue) is very common post stroke', stroke survivors acknowledged fatigue as an after-effect of stroke. One post from a survivor held that 'tiredness is common and can last for years post stroke'. Normalisation was a recurring response to queries about post-stroke fatigue, demonstrated by the stroke survivor who wrote 'the exhaustion as other posts have said is normal'.

***Fighting Post-Stroke Fatigue:* "Unwelcome guest"**

In contrast, a minority of Talkstroke forum users considered post-stroke fatigue to be 'one of those things we have to try and combat'. Forum users received advice from some stroke survivors to 'not give into it' – to be 'continually fighting what's going on' and to 'find your inner strength, [don't] let anything beat you'. Forum posts of a combative nature described the tiredness as 'annoying', emphasising that the 'point is not to give into it, [but] to find ways, little ways, to fight'. Despite this, such posts acknowledged that 'tiredness after stroke is very common', much the same as the forum users accepting and normalising their post-stroke fatigue.

***Survivors' biological explanations and beliefs:* "Brain healing"**

Most commonly, forum users attributed post-stroke fatigue to 'the brain healing'. We identified several variations on this theme: some stroke survivors and care-givers understood it as 'giving the brain the "time off" it needs to start healing itself', while others suggested that the 'body is working overtime trying to make sense of what has happened and heal as fast as it can'. There were also

references to information about post-stroke fatigue provided by health care professionals. On one occasion, the phrase 'post-stroke fatigue' was employed, where a relative explained he was told by a health care professional that his father in law 'may have post-stroke fatigue'. However, discussions usually centred around the explanation of symptoms given by health care professionals; that 'stroke causes fatigue'. Forum users sought to extend such explanations using metaphor for the disease process: 'the clock in your head…is going round at its own pace now', and expressed reverence for the brain; 'a strange thing' they could not understand.

***How survivors cope with post-stroke fatigue:* "Pace yourself"**

Forum posts discussing tiredness often mentioned or sought advice on how to cope with post-stroke fatigue. There was much discussion about involving health care professionals to assist with post-stroke fatigue management. Often, health care professionals were approached for support with the practicalities of returning to employment after stroke. For instance, one user reported that 'my GP doesn't really have any opinion on the tiredness (but is happy to keep signing me off from work)'. Another survivor was supported by forum users posting that 'just because your doctor cannot help [with the tiredness] it does not mean the be all and end all.' Forum users recommended simple practical solutions such as 'pacing yourself' rather than approaching health care professionals for support in managing the fatigue itself. The online community suggested a plethora of lifestyle modifications to manage fatigue including 'learning to live within your new limitations and taking it easy when needed'.

For some stroke survivors, post-stroke fatigue represents an emotional struggle. One user described being pleased with his progress yet was annoyed at himself for concentrating on his 'physical recovery' without taking his 'mental recovery' into account. Included in his 'mental recovery' was the idea of 'bouts of fatigue' that 'knocked [him] for six'. Yet for others, overcoming the fatigue was considered part of the physical recovery from stroke. One survivor reported that 'apart from tiredness and intermittent vertigo the physical effects of a stroke . . . have thankfully passed'.

Summary

Table 1 includes fragments of quotes and paraphrasing of comments from the Talkstroke forum representative of our six themes.

Table 1. Themes based on exemplar quotes from the Talkstroke Forum archives. PSF = post-stroke fatigue.

Discussion

For stroke survivors and their care-givers the forum provided legitimacy by acknowledging the existence of post-stroke fatigue, as well as offering management strategies based on lived experience. The homogeneity of forum users' interpretations of post-stroke fatigue is of particular note - the symptoms were repeatedly described as a 'legacy of stroke', and the existence of post-stroke fatigue in this online community was rarely, if ever, questioned.

Forum users reported a number of conflicting approaches to managing fatigue with some patients being told by their healthcare providers to rest and others being given no information at all. Commonly included in such posts were quotes to the effect that post-stroke fatigue was 'not understood by the medical profession'. As a result, stroke survivors and care-givers would seek out and offer their own, often metaphorical, explanations. The reported lack of medical consensus over approaches to post-stroke fatigue reflects an absence of a standardised approach to post-stroke fatigue in the medical setting.

Strengths and Limitations

This paper is the first to explore post-stroke fatigue from the perspective of stroke survivors and care-givers through an online forum. Previous qualitative studies have found online forums to constitute a rich and important data source, where patient perspectives are given in open discussion in the absence of a researcher[16]. As such, the insights into post-stroke fatigue gathered in our study provide a useful and valid contribution to the understanding of this common and debilitating problem.

A further strength of this study is that it employed a 'naturalistic' data collection methodology[16]. Using an archived online forum means our data were created from natural interactions between fellow forum users, rather than from pre-defined or guided discussions with researchers, thus removing participant bias toward the research agenda[21]. Therefore, we believe that this approach has enabled us to best elicit understandings and approaches to post-stroke fatigue from the perspective of stroke survivors and their care-givers.

A potential limitation of this study is that forum users may not be typical of all stroke survivors. Participants tend to be younger and less severely affected by stroke[17, 21]. It is possible that the constructs of post-stroke fatigue derived from our analysis of the forum posts are only representative of the beliefs of a self-selecting group of forum users.

Comparison to other literature

Post-stroke fatigue is reported as one of the largest unmet needs in stroke survivors[5]. Despite this, fatigue is not covered in a major way in prominent clinical guidelines[20, 23-25]. This is largely due to the lack of high-quality studies and methodological variation evident in the post-stroke fatigue literature[22]. In a report by the European Stroke Organisation on evidence-based stroke rehabilitation, although several topics are discussed, fatigue is noticeably missing[23]. The absence of

guidance for clinicians working with this population is reflected in the absence of a standardised approach as was apparent in the online forum posts.

Analysis of online community content is arguably an under-used research design, despite being found to potentially offer additional insight to traditional interviews[16]. Other research utilising the TalkStroke forum archives have been found to compliment evidence collected employing other research designs[26]. Balasooriya-Smeekens' 2016 study found that residual impairments, including fatigue, affected stroke survivors' return to work. Forum users also discussed a multitude of other difficulties stemming from fatigue including feeling misunderstood and suffering from an 'invisible disability'[26]. Our analysis found forum users referred to fatigue in this way. Balasooriya-Smeekens' study also alluded to the frequency of individuals experiencing fatigue after a stroke event, with over half of the forum users posting about occupation difficulties also pinpointing fatigue as an important factor. Recent research has examined factors associated with post-stroke fatigue and found reduced independence in activities of daily living and higher anxiety levels had a direct association with level of fatigue[27].

Implications

The array of conceptualisation and approaches to managing post-stroke fatigue identified in this analysis highlights the need for better evidence on how to optimise the recovery process for stroke survivors with fatigue and their care-givers. There is a lack of consistent understanding and explanation provided by health care professionals. Our data suggest that some stroke patients use the on-line community of stroke survivors and care-givers to provide informal explanations and reassurance. The lay beliefs that fatigue is 'due to the brain healing', and the importance of resting, highlight a gap between clinical and community knowledge. Better understanding by health care professionals of these lay beliefs may help them support their patients.

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Author contributions: ADS and KT contributed to the initial design of the study. KT and CG conducted data analysis and theme creation. KT and CG wrote the initial manuscript. ADS, JM and RM reviewed and contributed to the final manuscript.

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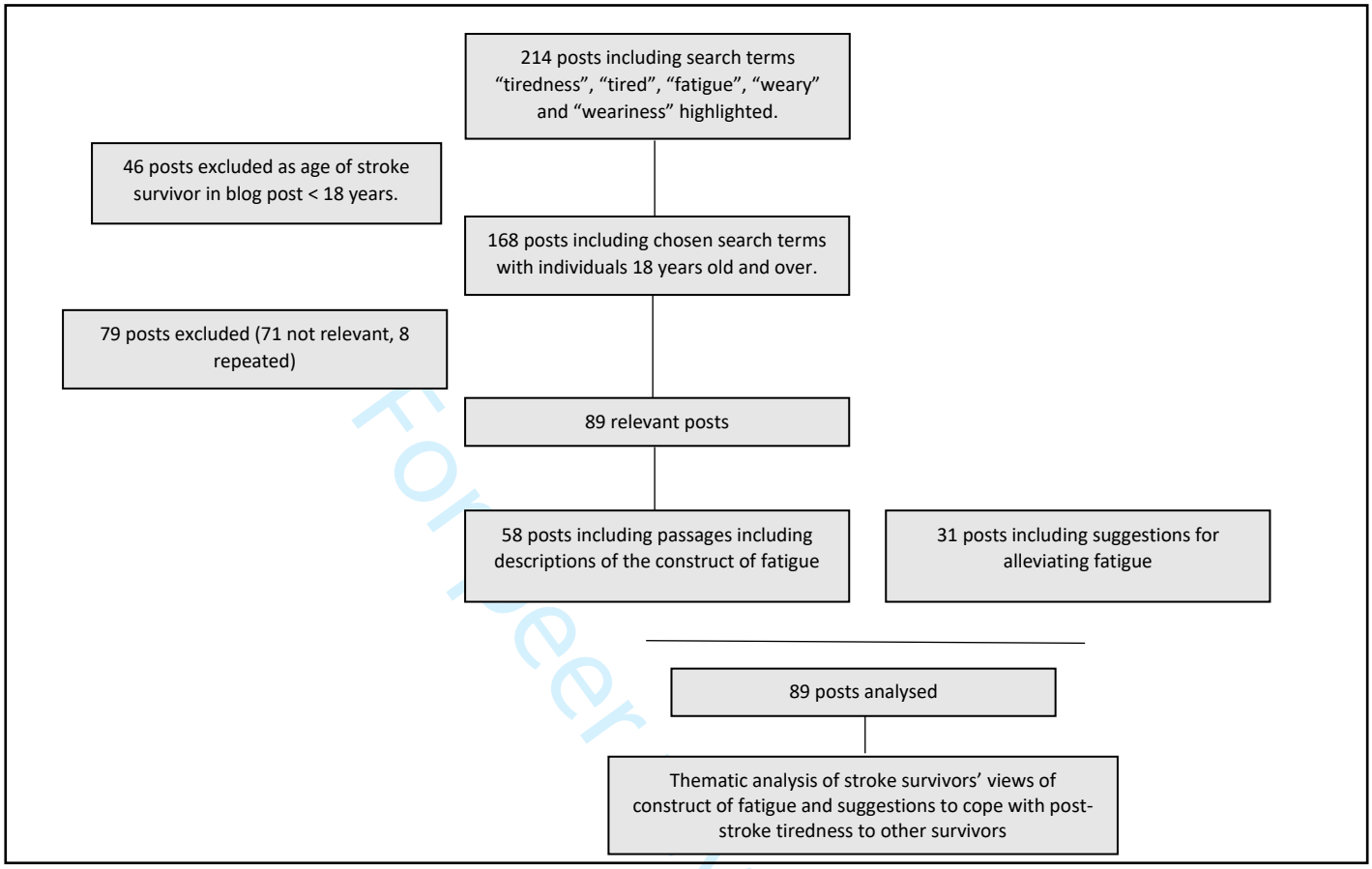
Figure 1. Flowchart of process for data selection and analysis.



Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

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	Reporting Item	Page Number
#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
#2	Summary of the key elements of the study using the abstract format of the intended publication; typically	2

		includes background, purpose, methods, results and conclusions	
Problem formulation	#3	Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	3-4
Purpose or research question	#4	Purpose of the study and specific objectives or questions	4
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.	4,9
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	10

Context	#7	Setting / site and salient contextual factors; rationale	2,4
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 saturation); rationale	4
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	4
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	4,5
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)	5
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and	5

		security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	5
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	5
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	5-8
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	5-8
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	8-9
Limitations	#19	Trustworthiness and limitations of findings	9
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were	10

		managed	
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	10

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Setting United Kingdom based web forum hosted by Stroke Association; TalkStroke. Archives from 2004-2011 were accessed.

Participants 65 stroke survivors and care-givers (61% female, 39% male, mean age 54) contributed to 89 relevant posts which included a relevant search term. This included 38 stroke survivors, 23 individuals in a family or carer role and 4 others who were unidentified.

Results Six themes were generated: 1. Medicalisation of Post-Stroke Fatigue: "a classic post-stroke symptom" , 2. A Tiredness Unique to Stroke: "a legacy of stroke", 3. Normalisation and Acceptance of Post-Stroke Fatigue: "part and parcel of stroke", 4. Fighting the Fatigue: "an unwelcome guest", 5. Survivors' and Care Givers' Biological Explanations: "the brain healing", 6. Coping Mechanisms: "pace yourself". Forum users also repeatedly commented that post-stroke fatigue was "not understood by the profession".

Conclusion This is the first study to employ data from an online forum to characterise post-stroke fatigue. Our data is considered naturalistic owing to the absence of a researcher guiding the discussion, and thus generates useful insights for healthcare professionals. Further research is required to translate this understanding of the patient and carer perspective into ways to improve management of post-stroke fatigue.

Key terms stroke, fatigue, rehabilitation, chronic illness, qualitative approaches

Article Summary

Strengths and limitations of this study

- **Strengths**

Analysis of data from an online community enables naturalistic data collection without the potential bias associated with research interviews.

This method of data collection employs direct analysis of posts written by stroke survivors and carers in the context of the forum, rather than in an "unnatural" research setting.

Using an online forum data set in this manner can complement traditional data collection techniques such as research interviews for qualitative research.

- **Limitations**

Forum users may not be typical of the stroke community – they tend to be younger and have less severe strokes (though this can be off-set by caregivers' contributions).

Introduction

Every year in the UK, 110,000 individuals experience a stroke[1]. Prevalence of fatigue after stroke has been reported to be as high as 70%, yet there is currently minimal evidence on which to base an effective management strategy[2-4]. Amongst stroke survivors living in the community with fatigue, 43% report this need as unmet[5]. Fatigue after stroke adversely affects survivors' quality of life, social participation, return to work and survival[2,6,7].

Better understanding of post-stroke fatigue would enable healthcare professionals to identify patients with clinically significant fatigue who may benefit from further investigation and support[6]. However, defining post-stroke fatigue is challenging due to its complex biopsychosocial elements and its 'inherent subjectivity'[8,9]. This may be mitigated by incorporating an improved understanding of survivors' perceptions into a working definition of post-stroke fatigue for health care professionals[10].

Post-stroke fatigue varies in its clinical presentation and the mechanisms that underlie it are poorly understood[11]. Some patients suffer from post-stroke fatigue for many years more than others with equivalent neurological damage[11]. There is some evidence to suggest that the experience of post-stroke fatigue is associated with factors such as anxiety, reduced quality of life and physical activity[12]. It has been proposed that post-stroke fatigue should be considered independently from other associated conditions such as depression, pain and sleep disorders[13]. Although post-stroke fatigue is highly subjective in nature, there is limited published research exploring the patient narrative[11]. A better understanding of the patient perspective within a biopsychosocial approach might facilitate a better understanding of the condition[14, 15].

Online forums provide a rich source of data from which subjective experiences of the issues pertinent to the population in question may be collected[16]. Online communities increasingly provide a platform for patients and care-givers to seek information, support, and discuss their conditions[17]. The resulting data are generated from natural interactions between fellow forum users rather than from guided discussions with researchers[17]. As such, analysis of online communities can uncover additional material in comparison to traditional qualitative methodologies[16].

This study aimed to understand post-stroke fatigue by analysis of discussions in an online forum dedicated to stroke survivors and their care-givers. We asked two research questions: (1) How is post-stroke fatigue described? and (2) What coping strategies are suggested to target post-stroke fatigue?

Methods

Design

This study employed thematic analysis of posts relating to post-stroke fatigue (PSF) written by stroke survivors and care-givers on the archived Talkstroke Forum. The moderated forum comprises 22,173 unique posts, 2583 usernames and was a UK-based online community hosted by the Stroke Association charity. We analysed archived forum posts including our primary search term "tiredness" and related terms "fatigue", "tired", "weary" and "weariness" from a total of 71 TalkStroke forum participants, written by stroke survivors and their care-givers between 2004-2011. All demographic data were extracted through reading of subsequent posts by each user and no information was taken from the individual registration process[17].

Patient and Public Involvement

Following initial review of the literature, researcher KT visited a Cambridgeshire based stroke group to discuss community-based patients understanding and experience of post-stroke fatigue. Initial research priorities were pitched to 18 individuals to decipher if the study research questions were thought to be important to the stroke survivor population. Individuals described the fatigue as overpowering and highlighted that when it hits, it is impossible to ignore. When asked about what hurdles they have faced following the stroke event one individual stated that they felt fatigue was the root of their other concerns. 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.

Ethics

The Stroke Association gave researcher ADS access to the forum archives and permission for the data to be used for research purposes. It is important to note that use of internet data raises ethical questions including considerations of intrusiveness and perceptions of a forum as public or private. Simoni and colleagues (2016) note that this specific analysis is classified as low intrusiveness and due

to the high number of users, participants were likely to view their posts as public. Talkstroke data were stored and accessed through the University of Cambridge Clinical School Secure Data Hosting Service (SDHS). People signing up to Talkstroke agreed that their data were public upon registering for the forum. To protect the identity and intellectual property of forum participants, we report fragments of responses and paraphrase longer discussion points.

Data Selection

Two researchers KT and CG searched the forum archives for the following search terms: "tiredness", "tired", "fatigue", "weary" and "weariness". Repeated and irrelevant posts were removed, as agreed by KT and CG through use of two rounds of coding and discussion. Posts with only a cursory mention of tiredness/fatigue or fatigue in relation to depression, pain or sleep disorders were excluded, as they strayed from the focus on fatigue as a direct consequence of stroke. Posts written by individuals under the age of 18 or by a parent figure describing their child were also removed since the focus of this study was adult stroke. This gave a preliminary data set of 104 posts written by 71 forum users. These posts were again screened by KT and CG to assess their relevance to the research questions and discussed until unanimous agreement was reached regarding the final data set, which comprised 89 posts written by 65 individuals.

Data Analysis

After reading all posts in the final data set to ensure familiarisation with the content, two researchers (KT and CG) carried out inductive thematic analysis to generate and refine emerging issues, using methods described by Braun and Clarke[18]. Posts were coded in order to answer the two research questions, by identifying the defining characteristics of post-stroke fatigue and revealing coping strategies. The majority (65%) of posts were coded by the first author (KT). Coding was performed independently for 30% of posts by the second author (CG). 5% of posts were coded by both researchers to ensure a consistent, systematic coding style was being used. Coding was discussed until agreement was reached for all posts to identify all pertinent key themes. These codes were aggregated into broader themes. During this process, both researchers revisited all extracts to ensure the suggested themes incorporated all data entries and thus the six final themes truly represented the complete data set. The process for data selection and analysis is summarised in Figure 1.

[Attached as separate file]

Figure 1. Flowchart of process for data selection and analysis.

Results

Participant Characteristics

65 individuals wrote 89 posts in the TalkStroke forum which included the selected search terms. This included 38 stroke survivors, 23 individuals in a family or carer role and 4 others who were unidentified. The above demographics specifically refer to stroke survivors either posting about their own experience or being referred to by a carer figure using the forum.

Themes

We identified six themes representing a wide variety of understanding and approaches to post-stroke fatigue by stroke survivors and care-givers alike. Following data familiarisation, using the 2 research questions, 62 initial codes were created and discussed to enable collation into the final six themes. KT and CG identified codes emerging from survivor and carer posts to check for differences and due to no clear variance identified, the final six themes were created encompassing both experiential viewpoints.

Medicalisation of Post-Stroke Fatigue: "A classic post stroke symptom"

Forum participants employed language highly suggestive of medicalisation such as 'suffers with fatigue'(Care Giver 4). Yet there was also much discussion about long-term effects of stroke as 'not understood by the profession'(Stroke Survivor 37). One individual reported attending two outpatient appointments following discharge from the stroke ward in which his fatigue was never addressed. This is at odds with the strongly held idea by many stroke survivors on the forum that 'tiredness is very much a part of stroke symptoms… a classic post-stroke symptom'(SS30). Notably, there is ample information about post stroke fatigue available online and in booklet format from various charitable organisations such as The Stroke Association and Chest, Heart & Stroke Scotland, but these recourses do not yet appear to be included in clinical practice, and were not mentioned in forum discussions.

Tiredness like no other: "A legacy of stroke"

A number of forum users discussed the features of post-stroke fatigue itself. It was described as 'a fatigue like no other'(CG3), and a 'neurological tiredness'(SS6). There were multiple references to the idea that 'stroke can and does cause fatigue'(SS36), that fatigue is 'a feature of our affliction'(SS9), and some took this further, characterising post-stroke fatigue as a distinct problem; 'a thing in itself, aside from chronic fatigue syndrome'(SS44). Further, fatigue was repeatedly expressed by forum users as a 'legacy of stroke'(SS45) or a 'typical post-stroke legacy'(SS12), encapsulating survivors' experiences of a long-lasting fatigue directly linked to the stroke.

***Acceptance and normalisation of Post-Stroke Fatigue*: "Part and parcel"**

Often, stroke survivors asked other forum users 'is this tiredness normal?'(SS3), obtaining a plethora of affirmative responses. This can be summarised by the idea proposed by one participant that post-stroke fatigue 'is a guest you're stuck with, you've just got to learn to live with it'(SS12), and that 'the feelings are normal and all stroke survivors can relate to the tiredness'(SS29). Along with the reassurance that 'tiredness (fatigue) is very common post stroke'(CG16), forum posters acknowledged fatigue as an after-effect of stroke. One post from a survivor held that 'tiredness is common and can last for years post stroke'(SS12). Normalisation was a recurring response to queries about post-stroke fatigue, demonstrated by the stroke survivor who wrote 'the exhaustion as other posts have said is normal'(SS5).

***Fighting Post-Stroke Fatigue:* "Unwelcome guest"**

In contrast, a minority of Talkstroke forum users considered post-stroke fatigue to be 'one of those things we have to try and combat'(SS17). Forum users received advice from some individuals to 'not give into it'(CG8) – to be 'continually fighting what's going on'(SS4) and to 'find your inner strength, [don't] let anything beat you'(CG2). Forum posts of a combative nature described the tiredness as 'annoying', emphasising that the 'point is not to give into it, [but] to find ways, little ways, to fight'(SS17). Despite this, such posts acknowledged that 'tiredness after stroke is very common'(SS20), much the same as the forum users accepting and normalising their post-stroke fatigue.

***Survivors' biological explanations and beliefs:* "Brain healing"**

Most commonly, forum users attributed post-stroke fatigue to 'the brain healing'(SS17). We identified several variations on this theme: some stroke survivors and care-givers understood it as 'giving the brain the "time off" it needs to start healing itself'(SS21), while others suggested that the 'body is working overtime trying to make sense of what has happened and heal as fast as it can'(CG16). There were also references to information about post-stroke fatigue provided by health care professionals. On one occasion, the phrase 'post-stroke fatigue' was employed, where a relative explained he was told by a health care professional that his father in law 'may have post-stroke fatigue'(CG17). However, discussions usually centred around the explanation of symptoms given by health care professionals; that 'stroke causes fatigue'(SS12). Forum users sought to extend such explanations using metaphor for the disease process: 'the clock in your head…is going round at its own pace now', and expressed reverence for the brain; 'a strange thing'(CG9) they could not understand.

***How survivors cope with post-stroke fatigue:* "Pace yourself"**

Forum posts discussing tiredness often mentioned or sought advice on how to cope with post-stroke fatigue. There was much discussion about involving health care professionals to assist with post-stroke fatigue management. Often, health care professionals were approached for support with the practicalities of returning to employment after stroke. For instance, one user reported that 'my GP doesn't really have any opinion on the tiredness (but is happy to keep signing me off from

work)'(SS27). Another survivor was supported by forum users posting that 'just because your doctor cannot help [with the tiredness] it does not mean the be all and end all'(SS5). Forum users recommended simple practical solutions such as 'pacing yourself'(CG15) rather than approaching health care professionals for support in managing the fatigue itself. The online community suggested a plethora of lifestyle modifications to manage fatigue including 'learning to live within your new limitations and taking it easy when needed'(SS12).

For some stroke survivors, post-stroke fatigue represents an emotional struggle. One user described being pleased with his progress yet was annoyed at himself for concentrating on his 'physical recovery' without taking his 'mental recovery'(SS8) into account. Included in his 'mental recovery' was the idea of 'bouts of fatigue' that 'knocked [him] for six'. Yet for others, overcoming the fatigue was considered part of the physical recovery from stroke. One survivor reported that 'apart from tiredness and intermittent vertigo the physical effects of a stroke . . . have thankfully passed'(SS14).

Summary

Table 1 includes fragments of quotes and paraphrasing of comments from the Talkstroke forum representative of our six themes.

Table 1. Themes based on exemplar quotes from the Talkstroke Forum archives. PSF = post-stroke fatigue. SS = Stroke Survivor. CG – Care Giver.

Discussion

For stroke survivors and their care-givers the forum provided legitimacy by acknowledging the existence of post-stroke fatigue, as well as offering management strategies based on lived experience. The homogeneity of forum users' interpretations of post-stroke fatigue is of particular note - the symptoms were repeatedly described as a 'legacy of stroke'(SS45), and the existence of post-stroke fatigue in this online community was rarely, if ever, questioned.

Forum users reported a number of conflicting approaches to managing fatigue with some patients being told by their healthcare providers to rest and others being given no information at all. Commonly included in such posts were quotes to the effect that post-stroke fatigue was 'not understood by the medical profession'(SS37). As a result, stroke survivors and care-givers would seek out and offer their own, often metaphorical, explanations. Understanding and defining fatigue in clinical settings has provided a challenge for many decades due to the complex interaction of biological, psychosocial and psychological elements, which makes understanding and management difficult for clinicians and patients alike[19]. The reported lack of medical consensus over approaches to post-stroke fatigue reflects an absence of a standardised approach to post-stroke fatigue in the medical setting. ambiguity extends to understanding of how fatigue after stroke occurs and what factors influence its onset and longevity This also holds true in literature exploring fatigue management with Wu's 2017 Cochrane review being the only review to seek answers to whether any intervention reduces the proportion of people with fatigue, fatigue severity or both. Methodological quality was poor throughout and no studies included primarily studied the effect on post-stroke

fatigue. Treatment modalities included pharmaceutical options such as fluoxetine, enerion and citicoline. Non-pharmaceutical options were a fatigue education programme, a mindfulness based stress reduction programme and continuous positive airway pressure (CPAP)[20].

Comparison to other literature

Post-stroke fatigue is reported as one of the largest unmet needs in stroke survivors[5]. Despite this, fatigue is not covered in a major way in prominent clinical guidelines[21-24]. This is largely due to the lack of high-quality studies and methodological variation evident in the post-stroke fatigue literature[25]. In a report by the European Stroke Organisation on evidence-based stroke rehabilitation, although several topics are discussed, fatigue is noticeably missing[23]. The absence of guidance for clinicians working with this population is reflected in the absence of a standardised approach as was apparent in the online forum posts.

Analysis of online community content is arguably an under-used research design, despite being found to potentially offer additional insight to traditional interviews[16]. Other research utilising the TalkStroke forum archives have been found to compliment evidence collected employing other research designs[26]. Balasooriya-Smeekens' 2016 study found that residual impairments, including fatigue, affected stroke survivors' return to work. Forum users also discussed a multitude of other difficulties stemming from fatigue including feeling misunderstood and suffering from an 'invisible disability'[26]. Our analysis found forum users referred to fatigue in this way. Balasooriya-Smeekens' study also alluded to the frequency of individuals experiencing fatigue after a stroke event, with over half of the forum users posting about occupation difficulties also pinpointing fatigue as an important factor. Recent research has examined factors associated with post-stroke fatigue and found reduced independence in activities of daily living and higher anxiety levels had a direct association with level of fatigue[27].

Strengths and Limitations

This paper is the first to explore post-stroke fatigue from the perspective of stroke survivors and care-givers through an online forum. Previous qualitative studies have found online forums to constitute a rich and important data source, where patient perspectives are given in open discussion in the absence of a researcher[16]. As such, the insights into post-stroke fatigue gathered in our study provide a useful and valid contribution to the understanding of this common and debilitating problem.

A further strength of this study is that it employed a 'naturalistic' data collection methodology[16]. Using an archived online forum means our data were created from natural interactions between fellow forum users, rather than from pre-defined or guided discussions with researchers, thus removing participant bias toward the research agenda[21]. Therefore, we believe that this approach has enabled

us to best elicit understandings and approaches to post-stroke fatigue from the perspective of stroke survivors and their care-givers.

A potential limitation of this study is that forum users may not be typical of all stroke survivors. Participants tend to be younger and less severely affected by stroke[17, 21]. It is possible that the constructs of post-stroke fatigue derived from our analysis of the forum posts are only representative of the beliefs of a self-selecting group of forum users. Forum users may also not represent all social classes, as De Simoni and colleagues highlighted by identifying over half of posters as holding professional occupations[17]. However, this information was only gathered from a minority of users so should be considered with caution.

By utilising a naturalistic data collection method, we were unable to identify the underlying cause of the fatigue that participants were discussing on the forum. Fatigue has been approached in this paper from a lay understanding, rather than from a 'medical model. There is a chance we were not able to exclude all forum posters under the age of 18 due to several participants having unknown age. The search terms utilised could also present a limitation, as Boolean operators were not used. Further qualitative research could incorporate a wider range of terms within the search strategy.

Implications

The array of conceptualisation and approaches to managing post-stroke fatigue identified in this analysis highlights the need for better evidence on how to optimise the recovery process for stroke survivors with fatigue and their care-givers. There is a lack of consistent understanding and explanation provided by health care professionals. Our data suggest that some stroke patients use the on-line community of stroke survivors and care-givers to provide informal explanations and reassurance. The lay beliefs that fatigue is 'due to the brain healing'(SS17), and the importance of resting, highlight a gap between clinical and community knowledge. Better understanding by health care professionals of these lay beliefs may help them support their patients.

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Figure Legends: Figure 1. Flowchart of process for data selection and analysis.

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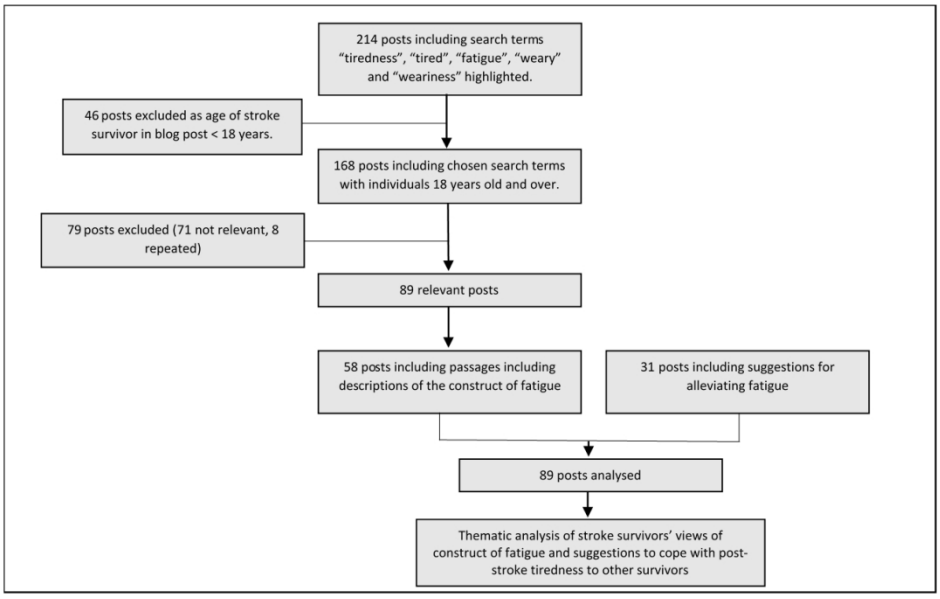

Figure 1. Flowchart of process for data selection and analysis.

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119x90mm (300 x 300 DPI)

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

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	Reporting Item	Page Number
#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
#2	Summary of the key elements of the study using the abstract format of the intended publication; typically	2

		includes background, purpose, methods, results and conclusions	
Problem formulation	#3	Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	3-4
Purpose or research question	#4	Purpose of the study and specific objectives or questions	4
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.	4,9
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	10

Context	#7	Setting / site and salient contextual factors; rationale	2,4
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 saturation); rationale	4
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	4
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	4,5
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)	5
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and	5

		security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	5
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	5
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	5-8
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	5-8
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	8-9
Limitations	#19	Trustworthiness and limitations of findings	9
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were	10

		managed	
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	10

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How is post-stroke fatigue understood by stroke survivors and carers? A thematic analysis of an online discussion forum

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How is post-stroke fatigue understood by stroke survivors and carers? A thematic analysis of an online discussion forum

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Word count: 3636

Objective To understand post-stroke fatigue from the perspective of stroke survivors and care-givers expressed in an online discussion forum.

Design. The search terms 'tiredness', 'fatigue', 'tired', 'weary' and 'weariness' were used to identify relevant posts. Thematic analysis performed by two independent researchers who coded all forum posts and identified pertinent themes.

Posts were coded in relation to two research questions; (1) How is post-stroke fatigue described? (2) What coping strategies are suggested to target post-stroke fatigue? Each theme was then summarised by a lead quotation in forum users' own words.

Setting UK based web forum hosted by Stroke Association; TalkStroke. Archives from 2004-2011 were accessed.

Participants 65 stroke survivors and care-givers (mean age 54, 61% female) contributed to 89 relevant posts which included a relevant search term. This included 38 stroke survivors, 23 individuals with family or carer role, 4 others unidentified.

Results Six themes were generated: 1. Medicalisation of Post-Stroke Fatigue: "a classic post-stroke symptom" , 2. A Tiredness Unique to Stroke: "a legacy of stroke", 3. Normalisation and Acceptance of Post-Stroke Fatigue: "part and parcel of stroke", 4. Fighting the Fatigue: "an unwelcome guest", 5. Survivors' and Care Givers' Biological Explanations: "the brain healing", 6. Coping Mechanisms: "pace yourself". Forum users also repeatedly commented that post-stroke fatigue was "not understood by the profession".

Conclusion This is the first study to employ data from an online forum to characterise post-stroke fatigue. Our data is considered naturalistic owing to the absence of a researcher guiding the discussion, and thus generates useful insights for healthcare professionals. Findings suggest a requirement for consistent understanding and explanation to be provided by healthcare professionals. The beliefs outlined here highlight the gap between clinical and community knowledge. Further research to translate understanding of patient and carer perspective into improved management of post-stroke fatigue is required.

Key terms stroke, fatigue, rehabilitation, chronic illness, qualitative approaches

Article Summary

Strengths and limitations of this study

- **Strengths**

Analysis of data from an online community enables naturalistic data collection without the potential bias associated with research interviews.

This method of data collection employs direct analysis of posts written by stroke survivors and carers in the context of the forum, rather than in an "unnatural" research setting.

Using an online forum data set in this manner can complement traditional data collection techniques such as research interviews for qualitative research.

- **Limitations**

Forum users may not be typical of the stroke community – they tend to be younger and have less severe strokes (though this can be off-set by caregivers' contributions).

Introduction

Every year in the UK, 110,000 individuals experience a stroke[1]. Prevalence of fatigue after stroke has been reported to be as high as 70%, yet there is currently minimal evidence on which to base an effective management strategy[2-4]. Amongst stroke survivors living in the community with fatigue, 43% report this need as unmet[5]. Fatigue after stroke adversely affects survivors' quality of life, social participation, return to work and survival[2,6,7].

Better understanding of post-stroke fatigue would enable healthcare professionals to identify patients with clinically significant fatigue who may benefit from further investigation and support[6]. However, defining post-stroke fatigue is challenging due to its complex biopsychosocial elements and its 'inherent subjectivity'[8,9]. This may be mitigated by incorporating an improved understanding of survivors' perceptions into a working definition of post-stroke fatigue for health care professionals[10].

Post-stroke fatigue varies in its clinical presentation and the mechanisms that underlie it are poorly understood[11]. Some patients suffer from post-stroke fatigue for many years more than others with equivalent neurological damage[11]. There is some evidence to suggest that the experience of post-stroke fatigue is associated with factors such as anxiety, reduced quality of life and physical activity[12]. It has been proposed that post-stroke fatigue should be considered independently from other associated conditions such as depression, pain and sleep disorders[13]. Although post-stroke fatigue is highly subjective in nature, there is limited published research exploring the patient

narrative[11]. A better understanding of the patient perspective within a biopsychosocial approach might facilitate a better understanding of the condition[14, 15].

Online forums provide a rich source of data from which subjective experiences of the issues pertinent to the population in question may be collected[16]. Online communities increasingly provide a platform for patients and care-givers to seek information, support, and discuss their conditions[17]. The resulting data are generated from natural interactions between fellow forum users rather than from guided discussions with researchers[17]. As such, analysis of online communities can uncover additional material in comparison to traditional qualitative methodologies[16].

This study aimed to understand post-stroke fatigue by analysis of discussions in an online forum dedicated to stroke survivors and their care-givers. We asked two research questions: (1) How is post-stroke fatigue described? and (2) What coping strategies are suggested to target post-stroke fatigue?

Methods

Design

This study employed thematic analysis of posts relating to post-stroke fatigue (PSF) written by stroke survivors and care-givers on the archived Talkstroke Forum. The moderated forum comprises 22,173 unique posts, 2583 usernames and was a UK-based online community hosted by the Stroke Association charity. We analysed archived forum posts including our primary search term “tiredness” and related terms “fatigue”, “tired”, “weary” and “weariness” from a total of 71 TalkStroke forum participants, written by stroke survivors and their care-givers between 2004-2011. All demographic data were extracted through reading of subsequent posts by each user and no information was taken from the individual registration process[17].

Patient and Public Involvement

Following initial review of the literature, researcher KT visited a Cambridgeshire based stroke group to discuss community-based patients understanding and experience of post-stroke fatigue. Initial research priorities were pitched to 18 individuals to decipher if the study research questions were thought to be important to the stroke survivor population. Individuals described the fatigue as overpowering and highlighted that when it hits, it is impossible to ignore. When asked about what hurdles they have faced following the stroke event one individual stated that they felt fatigue was the root of their other concerns. 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.

Ethics

The Stroke Association gave researcher ADS access to the forum archives and permission for the data to be used for research purposes. It is important to note that use of internet data raises ethical

questions including considerations of intrusiveness and perceptions of a forum as public or private. Simoni and colleagues (2016) note that this specific analysis is classified as low intrusiveness and due to the high number of users, participants were likely to view their posts as public. Talkstroke data were stored and accessed through the University of Cambridge Clinical School Secure Data Hosting Service (SDHS). People signing up to Talkstroke agreed that their data were public upon registering for the forum. To protect the identity and intellectual property of forum participants, we report fragments of responses and paraphrase longer discussion points.

Data Selection

Two researchers KT and CG searched the forum archives for the following search terms: "tiredness", "tired", "fatigue", "weary" and "weariness". Repeated and irrelevant posts were removed, as agreed by KT and CG through use of two rounds of coding and discussion. Posts with only a cursory mention of tiredness/fatigue or fatigue in relation to depression, pain or sleep disorders were excluded, as they strayed from the focus on fatigue as a direct consequence of stroke. Posts written by individuals under the age of 18 or by a parent figure describing their child were also removed since the focus of this study was adult stroke. This gave a preliminary data set of 104 posts written by 71 forum users. These posts were again screened by KT and CG to assess their relevance to the research questions and discussed until unanimous agreement was reached regarding the final data set, which comprised 89 posts written by 65 individuals.

Data Analysis

After reading all posts in the final data set to ensure familiarisation with the content, two researchers (KT and CG) carried out inductive thematic analysis to generate and refine emerging issues, using methods described by Braun and Clarke[18]. Posts were coded in order to answer the two research questions, by identifying the defining characteristics of post-stroke fatigue and revealing coping strategies. The majority (65%) of posts were coded by the first author (KT). Coding was performed independently for 30% of posts by the second author (CG). 5% of posts were coded by both researchers to ensure a consistent, systematic coding style was being used. Coding was discussed until agreement was reached for all posts to identify all pertinent key themes. These codes were aggregated into broader themes. During this process, both researchers revisited all extracts to ensure the suggested themes incorporated all data entries and thus the six final themes truly represented the complete data set. The process for data selection and analysis is summarised in Figure 1.

[Attached as separate file]

Figure 1. Flowchart of process for data selection and analysis.

Results

Participant Characteristics

65 individuals wrote 89 posts in the TalkStroke forum which included the selected search terms. This included 38 stroke survivors, 23 individuals in a family or carer role and 4 others who were unidentified. The above demographics specifically refer to stroke survivors either posting about their own experience or being referred to by a carer figure using the forum.

Themes

We identified six themes representing a wide variety of understanding and approaches to post-stroke fatigue by stroke survivors and care-givers alike. Following data familiarisation, using the 2 research questions, 62 initial codes were created and discussed to enable collation into the final six themes. KT and CG identified codes emerging from survivor and carer posts to check for differences and due to no clear variance identified, the final six themes were created encompassing both experiential viewpoints.

Medicalisation of Post-Stroke Fatigue: "A classic post stroke symptom"

Forum participants employed language highly suggestive of medicalisation such as 'suffers with fatigue'(Care Giver 4). Yet there was also much discussion about long-term effects of stroke as 'not understood by the profession'(Stroke Survivor 37). One individual reported attending two outpatient appointments following discharge from the stroke ward in which his fatigue was never addressed. This is at odds with the strongly held idea by many stroke survivors on the forum that 'tiredness is very much a part of stroke symptoms… a classic post-stroke symptom'(SS30). Notably, there is ample information about post stroke fatigue available online and in booklet format from various charitable organisations such as The Stroke Association and Chest, Heart & Stroke Scotland, but these recourses do not yet appear to be included in clinical practice, and were not mentioned in forum discussions.

Tiredness like no other: "A legacy of stroke"

A number of forum users discussed the features of post-stroke fatigue itself. It was described as 'a fatigue like no other'(CG3), and a 'neurological tiredness'(SS6). There were multiple references to the idea that 'stroke can and does cause fatigue'(SS36), that fatigue is 'a feature of our affliction'(SS9), and some took this further, characterising post-stroke fatigue as a distinct problem; 'a thing in itself, aside from chronic fatigue syndrome'(SS44). Further, fatigue was repeatedly expressed by forum users as a 'legacy of stroke'(SS45) or a 'typical post-stroke legacy'(SS12), encapsulating survivors' experiences of a long-lasting fatigue directly linked to the stroke.

***Acceptance and normalisation of Post-Stroke Fatigue*: "Part and parcel"**

Often, stroke survivors asked other forum users 'is this tiredness normal?'(SS3), obtaining a plethora of affirmative responses. This can be summarised by the idea proposed by one participant that post-stroke fatigue 'is a guest you're stuck with, you've just got to learn to live with it'(SS12), and that 'the feelings are normal and all stroke survivors can relate to the tiredness'(SS29). Along with the reassurance that 'tiredness (fatigue) is very common post stroke'(CG16), forum posters acknowledged fatigue as an after-effect of stroke. One post from a survivor held that 'tiredness is common and can last for years post stroke'(SS12). Normalisation was a recurring response to queries about post-stroke fatigue, demonstrated by the stroke survivor who wrote 'the exhaustion as other posts have said is normal'(SS5).

***Fighting Post-Stroke Fatigue:* "Unwelcome guest"**

In contrast, some Talkstroke forum users considered post-stroke fatigue to be 'one of those things we have to try and combat'(SS17). Forum users received advice from some individuals to 'not give into it'(CG8) – to be 'continually fighting what's going on'(SS4) and to 'find your inner strength, [don't] let anything beat you'(CG2). Forum posts of a combative nature described the tiredness as 'annoying', emphasising that the 'point is not to give into it, [but] to find ways, little ways, to fight'(SS17). Despite this, such posts acknowledged that 'tiredness after stroke is very common'(SS20), much the same as the forum users accepting and normalising their post-stroke fatigue.

***Survivors' biological explanations and beliefs:* "Brain healing"**

Most commonly, forum users attributed post-stroke fatigue to 'the brain healing'(SS17). We identified several variations on this theme: some stroke survivors and care-givers understood it as 'giving the brain the "time off" it needs to start healing itself'(SS21), while others suggested that the 'body is working overtime trying to make sense of what has happened and heal as fast as it can'(CG16). There were also references to information about post-stroke fatigue provided by health care professionals. On one occasion, the phrase 'post-stroke fatigue' was employed, where a relative explained he was told by a health care professional that his father in law 'may have post-stroke fatigue'(CG17). However, discussions usually centred around the explanation of symptoms given by health care professionals; that 'stroke causes fatigue'(SS12). Forum users sought to extend such explanations using metaphor for the disease process: 'the clock in your head…is going round at its own pace now', and expressed reverence for the brain; 'a strange thing'(CG9) they could not understand.

***How survivors cope with post-stroke fatigue:* "Pace yourself"**

Forum posts discussing tiredness often mentioned or sought advice on how to cope with post-stroke fatigue. There was much discussion about involving health care professionals to assist with post-

stroke fatigue management. Often, health care professionals were approached for support with the practicalities of returning to employment after stroke. For instance, one user reported that 'my GP doesn't really have any opinion on the tiredness (but is happy to keep signing me off from work)'(SS27). Another survivor was supported by forum users posting that 'just because your doctor cannot help [with the tiredness] it does not mean the be all and end all'(SS5). Forum users recommended simple practical solutions such as 'pacing yourself'(CG15) rather than approaching health care professionals for support in managing the fatigue itself. The online community suggested a plethora of lifestyle modifications to manage fatigue including 'learning to live within your new limitations and taking it easy when needed'(SS12).

For some stroke survivors, post-stroke fatigue represents an emotional struggle. One user described being pleased with his progress yet was annoyed at himself for concentrating on his 'physical recovery' without taking his 'mental recovery'(SS8) into account. Included in his 'mental recovery' was the idea of 'bouts of fatigue' that 'knocked [him] for six'. Yet for others, overcoming the fatigue was considered part of the physical recovery from stroke. One survivor reported that 'apart from tiredness and intermittent vertigo the physical effects of a stroke . . . have thankfully passed'(SS14).

Summary

Table 1 includes fragments of quotes and paraphrasing of comments from the Talkstroke forum representative of our six themes.

Table 1. Themes based on exemplar quotes from the Talkstroke Forum archives. PSF = post-stroke fatigue. SS = Stroke Survivor. CG – Care Giver.

Discussion

For stroke survivors and their care-givers the forum provided legitimacy by acknowledging the existence of post-stroke fatigue, as well as offering management strategies based on lived experience. The homogeneity of forum users' interpretations of post-stroke fatigue is of particular note - the symptoms were repeatedly described as a 'legacy of stroke'(SS45), and the existence of post-stroke fatigue in this online community was rarely, if ever, questioned.

Forum users reported a number of conflicting approaches to managing fatigue with some patients being told by their healthcare providers to rest and others being given no information at all. Commonly included in such posts were quotes to the effect that post-stroke fatigue was 'not understood by the medical profession'(SS37). As a result, stroke survivors and care-givers would seek out and offer their own, often metaphorical, explanations. Understanding and defining fatigue in clinical settings has provided a challenge for many decades due to the complex interaction of biological, psychosocial and psychological elements, which makes understanding and management difficult for clinicians and patients alike[19]. The reported lack of medical consensus over approaches to post-stroke fatigue reflects an absence of a standardised approach to post-stroke fatigue in the medical setting. ambiguity extends to understanding of how fatigue after stroke occurs and what factors influence its onset and longevity This also holds true in literature exploring fatigue

management with Wu's 2015 Cochrane review being the only review to seek answers to whether any intervention reduces the proportion of people with fatigue, fatigue severity or both. Methodological quality was poor throughout and no studies included primarily studied the effect on post-stroke fatigue. Treatment modalities included pharmaceutical options such as fluoxetine, enerion and citicoline. Non-pharmaceutical options were a fatigue education programme, a mindfulness based stress reduction programme and continuous positive airway pressure (CPAP)[20].

Comparison to other literature

Post-stroke fatigue is reported as one of the largest unmet needs in stroke survivors[5]. Despite this, fatigue is only recently starting to be included within prominent clinical guidelines[21-24]. This is largely due to the lack of high-quality studies and methodological variation evident in the post-stroke fatigue literature[25]. In a report by the European Stroke Organisation on evidence-based stroke rehabilitation, although several topics are discussed, fatigue is noticeably missing[23]. The absence of guidance for clinicians working with this population is reflected in the absence of a standardised approach as was apparent in the online forum posts.

Analysis of online community content is arguably an under-used research design, despite being found to potentially offer additional insight to traditional interviews[16]. Other research utilising the TalkStroke forum archives have been found to compliment evidence collected employing other research designs[26]. Balasooriya-Smeekens' 2016 study found that residual impairments, including fatigue, affected stroke survivors' return to work. Forum users also discussed a multitude of other difficulties stemming from fatigue including feeling misunderstood and suffering from an 'invisible disability'[26]. Our analysis found forum users referred to fatigue in this way. Balasooriya-Smeekens' study also alluded to the frequency of individuals experiencing fatigue after a stroke event, with over half of the forum users posting about occupation difficulties also pinpointing fatigue as an important factor. Recent research has examined factors associated with post-stroke fatigue and found reduced independence in activities of daily living and higher anxiety levels had a direct association with level of fatigue[27].

Strengths and Limitations

This paper is the first to explore post-stroke fatigue from the perspective of stroke survivors and care-givers through an online forum. Previous qualitative studies have found online forums to constitute a rich and important data source, where patient perspectives are given in open discussion in the absence of a researcher[16]. As such, the insights into post-stroke fatigue gathered in our study provide a useful and valid contribution to the understanding of this common and debilitating problem.

A further strength of this study is that it employed a 'naturalistic' data collection methodology[16]. Using an archived online forum means our data were created from natural interactions between fellow forum users, rather than from pre-defined or guided discussions with researchers, thus removing participant bias toward the research agenda[21]. Therefore, we believe that this approach has enabled us to best elicit understandings and approaches to post-stroke fatigue from the perspective of stroke survivors and their care-givers.

A potential limitation of this study is that forum users may not be typical of all stroke survivors. Participants tend to be younger and less severely affected by stroke[17, 21]. It is possible that the constructs of post-stroke fatigue derived from our analysis of the forum posts are only representative of the beliefs of a self-selecting group of forum users. Forum users may also not represent all social classes, as De Simoni and colleagues highlighted by identifying over half of posters as holding professional occupations[17]. However, this information was only gathered from a minority of users so should be considered with caution. Furthermore, the data collected was from archives dated before 2012. Qualitative research has been published since this date and so this may not represent current understanding of post-stroke fatigue. This is however, the most recent study investigating the topic within an online community.

By utilising a naturalistic data collection method, we were unable to identify the underlying cause of the fatigue that participants were discussing on the forum. Fatigue has been approached in this paper from a lay understanding, rather than from a 'medical model. There is a chance we were not able to exclude all forum posters under the age of 18 due to several participants having unknown age. The search terms utilised could also present a limitation, as Boolean operators were not used. Further qualitative research could incorporate a wider range of terms within the search strategy.

Implications

'The array of conceptualisation and approaches to managing post-stroke fatigue identified in this analysis highlights the need for better evidence on how to optimise the recovery process for stroke survivors with fatigue and their care-givers. Our data suggest that some stroke patients use the on-line community of stroke survivors and care-givers to provide informal explanations and reassurance. The construct of PSF as a 'tiredness like no other' (SS6) that 'everybody seems to suffer with' (SS24) suggests a requirement for a consistent understanding and explanation to be provided by healthcare professionals, reducing the reliance of sufferers to seek informal explanations and reassurance from within the stroke community. Capturing the most prevalent beliefs, largely that fatigue is 'due to the brain healing' (SS17) enables assessment of the gap between clinical and community knowledge informing the education required to better inform survivors. Better understanding by health care professionals of these lay beliefs may help them support their patients.'

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Author contributions: ADS and KT contributed to the initial design of the study. KT and CG conducted data analysis and theme creation. KT and CG wrote the initial manuscript. ADS, JM and RM reviewed and contributed to the final manuscript.

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Competing interests: None declared.

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

Data sharing statement: No additional data are available.

Figure Legends: Figure 1. Flowchart of process for data selection and analysis.

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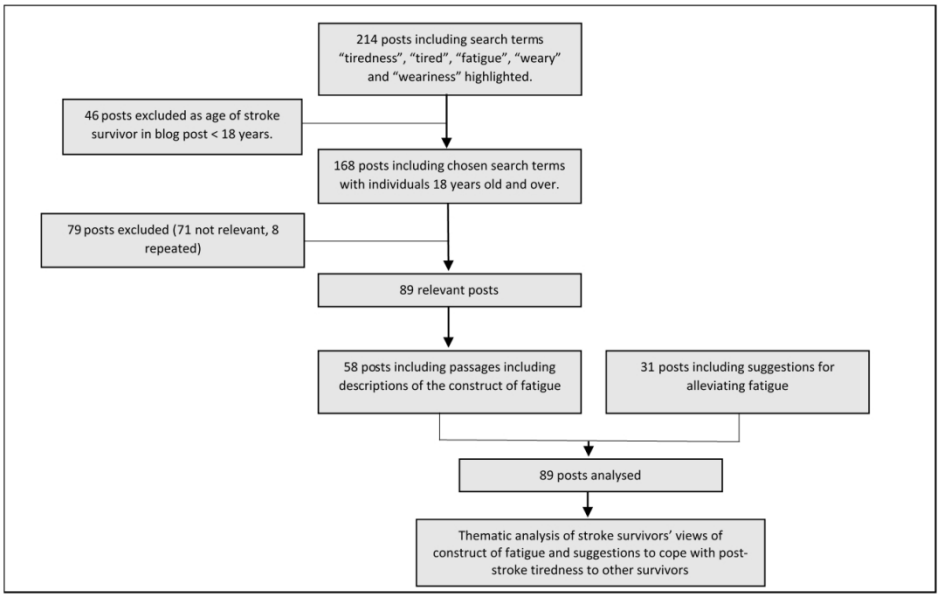

Figure 1. Flowchart of process for data selection and analysis.

Figure 1. Flowchart of process for data selection and analysis

119x90mm (300 x 300 DPI)

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

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O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

	Reporting Item	Page Number
#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
#2	Summary of the key elements of the study using the abstract format of the intended publication; typically	2

		includes background, purpose, methods, results and conclusions	
Problem formulation	#3	Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	3-4
Purpose or research question	#4	Purpose of the study and specific objectives or questions	4
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.	4,9
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	10

Context	#7	Setting / site and salient contextual factors; rationale	2,4
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 saturation); rationale	4
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	4
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	4,5
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)	5
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and	5

		security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	5
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	5
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	5-8
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	5-8
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	8-9
Limitations	#19	Trustworthiness and limitations of findings	9
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were	10

		managed	
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	10

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How is post-stroke fatigue understood by stroke survivors and carers? A thematic analysis of an online discussion forum

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How is post-stroke fatigue understood by stroke survivors and carers? A thematic analysis of an online discussion forum

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Objective To understand post-stroke fatigue from the perspective of stroke survivors and care-givers expressed in an online discussion forum.

Design. The search terms 'tiredness', 'fatigue', 'tired', 'weary' and 'weariness' were used to identify relevant posts. Thematic analysis performed by two independent researchers who coded all forum posts and identified pertinent themes.

Posts were coded in relation to two research questions; (1) How is post-stroke fatigue described? (2) What coping strategies are suggested to target post-stroke fatigue? Each theme was then summarised by a lead quotation in forum users' own words.

Setting UK based web forum hosted by Stroke Association; TalkStroke. Archives from 2004-2011 were accessed.

Participants 65 stroke survivors and care-givers (mean age 54, 61% female) contributed to 89 relevant posts which included a relevant search term. This included 38 stroke survivors, 23 individuals with family or carer role, 4 others unidentified.

Results Six themes were generated: 1. Medicalisation of Post-Stroke Fatigue: "a classic post-stroke symptom" , 2. A Tiredness Unique to Stroke: "a legacy of stroke", 3. Normalisation and Acceptance of Post-Stroke Fatigue: "part and parcel of stroke", 4. Fighting the Fatigue: "an unwelcome guest", 5. Survivors' and Care Givers' Biological Explanations: "the brain healing", 6. Coping Mechanisms: "pace yourself". Forum users also repeatedly commented that post-stroke fatigue was "not understood by the profession".

Conclusion This is the first study to employ data from an online forum to characterise post-stroke fatigue. Our data is considered naturalistic owing to the absence of a researcher guiding the discussion, and thus generates useful insights for healthcare professionals. Findings suggest a requirement for consistent understanding and explanation to be provided by healthcare professionals. The beliefs outlined here highlight the gap between clinical and community knowledge. Further research to translate understanding of patient and carer perspective into improved management of post-stroke fatigue is required.

Key terms stroke, fatigue, rehabilitation, chronic illness, qualitative approaches

Article Summary

Strengths and limitations of this study

- **Strengths**

Analysis of data from an online community enables naturalistic data collection without the potential bias associated with research interviews.

This method of data collection employs direct analysis of posts written by stroke survivors and carers in the context of the forum, rather than in an "unnatural" research setting.

Using an online forum data set in this manner can complement traditional data collection techniques such as research interviews for qualitative research.

- **Limitations**

Forum users may not be typical of the stroke community – they tend to be younger and have less severe strokes (though this can be off-set by caregivers' contributions).

Introduction

Every year in the UK, 110,000 individuals experience a stroke[1]. Prevalence of fatigue after stroke has been reported to be as high as 70%, yet there is currently minimal evidence on which to base an effective management strategy[2-4]. Amongst stroke survivors living in the community with fatigue, 43% report this need as unmet[5]. Fatigue after stroke adversely affects survivors' quality of life, social participation, return to work and survival[2,6,7].

Better understanding of post-stroke fatigue would enable healthcare professionals to identify patients with clinically significant fatigue who may benefit from further investigation and support[6]. However, defining post-stroke fatigue is challenging due to its complex biopsychosocial elements and its 'inherent subjectivity'[8,9]. This may be mitigated by incorporating an improved understanding of survivors' perceptions into a working definition of post-stroke fatigue for health care professionals[10].

Post-stroke fatigue varies in its clinical presentation and the mechanisms that underlie it are poorly understood[11]. Some patients suffer from post-stroke fatigue for many years more than others with equivalent neurological damage[11]. There is some evidence to suggest that the experience of post-stroke fatigue is associated with factors such as anxiety, reduced quality of life and physical activity[12]. It has been proposed that post-stroke fatigue should be considered independently from other associated conditions such as depression, pain and sleep disorders[13]. Although post-stroke fatigue is highly subjective in nature, there is limited published research exploring the patient

narrative[11]. A better understanding of the patient perspective within a biopsychosocial approach might facilitate a better understanding of the condition[14, 15].

Online forums provide a rich source of data from which subjective experiences of the issues pertinent to the population in question may be collected[16]. Online communities increasingly provide a platform for patients and care-givers to seek information, support, and discuss their conditions[17]. The resulting data are generated from natural interactions between fellow forum users rather than from guided discussions with researchers[17]. As such, analysis of online communities can uncover additional material in comparison to traditional qualitative methodologies[16].

This study aimed to understand post-stroke fatigue by analysis of discussions in an online forum dedicated to stroke survivors and their care-givers. We asked two research questions: (1) How is post-stroke fatigue described? and (2) What coping strategies are suggested to target post-stroke fatigue?

Methods

Design

This study employed thematic analysis of posts relating to post-stroke fatigue (PSF) written by stroke survivors and care-givers on the archived Talkstroke Forum. The moderated forum comprises 22,173 unique posts, 2583 usernames and was a UK-based online community hosted by the Stroke Association charity. We analysed archived forum posts including our primary search term “tiredness” and related terms “fatigue”, “tired”, “weary” and “weariness” from a total of 71 TalkStroke forum participants, written by stroke survivors and their care-givers between 2004-2011. All demographic data were extracted through reading of subsequent posts by each user and no information was taken from the individual registration process[17].

Patient and Public Involvement

Following initial review of the literature, researcher KT visited a Cambridgeshire based stroke group to discuss community-based patients understanding and experience of post-stroke fatigue. Initial research priorities were pitched to 18 individuals to decipher if the study research questions were thought to be important to the stroke survivor population. Individuals described the fatigue as overpowering and highlighted that when it hits, it is impossible to ignore. When asked about what hurdles they have faced following the stroke event one individual stated that they felt fatigue was the root of their other concerns. 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.

Ethics

The Stroke Association gave researcher ADS access to the forum archives and permission for the data to be used for research purposes. It is important to note that use of internet data raises ethical

questions including considerations of intrusiveness and perceptions of a forum as public or private. Simoni and colleagues (2016) note that this specific analysis is classified as low intrusiveness and due to the high number of users, participants were likely to view their posts as public. Talkstroke data were stored and accessed through the University of Cambridge Clinical School Secure Data Hosting Service (SDHS). People signing up to Talkstroke agreed that their data were public upon registering for the forum. To protect the identity and intellectual property of forum participants, we report fragments of responses and paraphrase longer discussion points.

Data Selection

Two researchers KT and CG searched the forum archives for the following search terms: "tiredness", "tired", "fatigue", "weary" and "weariness". Repeated and irrelevant posts were removed, as agreed by KT and CG through use of two rounds of coding and discussion. Posts with only a cursory mention of tiredness/fatigue or fatigue in relation to depression, pain or sleep disorders were excluded, as they strayed from the focus on fatigue as a direct consequence of stroke. Posts written by individuals under the age of 18 or by a parent figure describing their child were also removed since the focus of this study was adult stroke. This gave a preliminary data set of 104 posts written by 71 forum users. These posts were again screened by KT and CG to assess their relevance to the research questions and discussed until unanimous agreement was reached regarding the final data set, which comprised 89 posts written by 65 individuals.

Data Analysis

After reading all posts in the final data set to ensure familiarisation with the content, two researchers (KT and CG) carried out inductive thematic analysis to generate and refine emerging issues, using methods described by Braun and Clarke[18]. Posts were coded in order to answer the two research questions, by identifying the defining characteristics of post-stroke fatigue and revealing coping strategies. The majority (65%) of posts were coded by the first author (KT). Coding was performed independently for 30% of posts by the second author (CG). 5% of posts were coded by both researchers to ensure a consistent, systematic coding style was being used. Coding was discussed until agreement was reached for all posts to identify all pertinent key themes. These codes were aggregated into broader themes. During this process, both researchers revisited all extracts to ensure the suggested themes incorporated all data entries and thus the six final themes truly represented the complete data set. The process for data selection and analysis is summarised in Figure 1.

[Attached as separate file]

Figure 1. Flowchart of process for data selection and analysis.

Results

Participant Characteristics

65 individuals wrote 89 posts in the TalkStroke forum which included the selected search terms. This included 38 stroke survivors, 23 individuals in a family or carer role and 4 others who were unidentified. The above demographics specifically refer to stroke survivors either posting about their own experience or being referred to by a carer figure using the forum.

Themes

We identified six themes representing a wide variety of understanding and approaches to post-stroke fatigue by stroke survivors and care-givers alike. Following data familiarisation, using the 2 research questions, 62 initial codes were created and discussed to enable collation into the final six themes. KT and CG identified codes emerging from survivor and carer posts to check for differences and due to no clear variance identified, the final six themes were created encompassing both experiential viewpoints.

Medicalisation of Post-Stroke Fatigue: "A classic post stroke symptom"

Forum participants employed language highly suggestive of medicalisation such as 'suffers with fatigue'(Care Giver 4). Yet there was also much discussion about long-term effects of stroke as 'not understood by the profession'(Stroke Survivor 37). One individual reported attending two outpatient appointments following discharge from the stroke ward in which his fatigue was never addressed. This is at odds with the strongly held idea by many stroke survivors on the forum that 'tiredness is very much a part of stroke symptoms… a classic post-stroke symptom'(SS30). Notably, there is ample information about post stroke fatigue available online and in booklet format from various charitable organisations such as The Stroke Association and Chest, Heart & Stroke Scotland, but these recourses do not yet appear to be included in clinical practice, and were not mentioned in forum discussions.

Tiredness like no other: "A legacy of stroke"

A number of forum users discussed the features of post-stroke fatigue itself. It was described as 'a fatigue like no other'(CG3), and a 'neurological tiredness'(SS6). There were multiple references to the idea that 'stroke can and does cause fatigue'(SS36), that fatigue is 'a feature of our affliction'(SS9), and some took this further, characterising post-stroke fatigue as a distinct problem; 'a thing in itself, aside from chronic fatigue syndrome'(SS44). Further, fatigue was repeatedly expressed by forum users as a 'legacy of stroke'(SS45) or a 'typical post-stroke legacy'(SS12), encapsulating survivors' experiences of a long-lasting fatigue directly linked to the stroke.

***Acceptance and normalisation of Post-Stroke Fatigue*: "Part and parcel"**

Often, stroke survivors asked other forum users 'is this tiredness normal?'(SS3), obtaining a plethora of affirmative responses. This can be summarised by the idea proposed by one participant that post-stroke fatigue 'is a guest you're stuck with, you've just got to learn to live with it'(SS12), and that 'the feelings are normal and all stroke survivors can relate to the tiredness'(SS29). Along with the reassurance that 'tiredness (fatigue) is very common post stroke'(CG16), forum posters acknowledged fatigue as an after-effect of stroke. One post from a survivor held that 'tiredness is common and can last for years post stroke'(SS12). Normalisation was a recurring response to queries about post-stroke fatigue, demonstrated by the stroke survivor who wrote 'the exhaustion as other posts have said is normal'(SS5).

***Fighting Post-Stroke Fatigue:* "Unwelcome guest"**

In contrast, some Talkstroke forum users considered post-stroke fatigue to be 'one of those things we have to try and combat'(SS17). Forum users received advice from some individuals to 'not give into it'(CG8) – to be 'continually fighting what's going on'(SS4) and to 'find your inner strength, [don't] let anything beat you'(CG2). Forum posts of a combative nature described the tiredness as 'annoying', emphasising that the 'point is not to give into it, [but] to find ways, little ways, to fight'(SS17). Despite this, such posts acknowledged that 'tiredness after stroke is very common'(SS20), much the same as the forum users accepting and normalising their post-stroke fatigue.

***Survivors' biological explanations and beliefs:* "Brain healing"**

Most commonly, forum users attributed post-stroke fatigue to 'the brain healing'(SS17). We identified several variations on this theme: some stroke survivors and care-givers understood it as 'giving the brain the "time off" it needs to start healing itself'(SS21), while others suggested that the 'body is working overtime trying to make sense of what has happened and heal as fast as it can'(CG16). There were also references to information about post-stroke fatigue provided by health care professionals. On one occasion, the phrase 'post-stroke fatigue' was employed, where a relative explained he was told by a health care professional that his father in law 'may have post-stroke fatigue'(CG17). However, discussions usually centred around the explanation of symptoms given by health care professionals; that 'stroke causes fatigue'(SS12). Forum users sought to extend such explanations using metaphor for the disease process: 'the clock in your head…is going round at its own pace now', and expressed reverence for the brain; 'a strange thing'(CG9) they could not understand.

***How survivors cope with post-stroke fatigue:* "Pace yourself"**

Forum posts discussing tiredness often mentioned or sought advice on how to cope with post-stroke fatigue. There was much discussion about involving health care professionals to assist with post-

stroke fatigue management. Often, health care professionals were approached for support with the practicalities of returning to employment after stroke. For instance, one user reported that 'my GP doesn't really have any opinion on the tiredness (but is happy to keep signing me off from work)'(SS27). Another survivor was supported by forum users posting that 'just because your doctor cannot help [with the tiredness] it does not mean the be all and end all'(SS5). Forum users recommended simple practical solutions such as 'pacing yourself'(CG15) rather than approaching health care professionals for support in managing the fatigue itself. The online community suggested a plethora of lifestyle modifications to manage fatigue including 'learning to live within your new limitations and taking it easy when needed'(SS12).

For some stroke survivors, post-stroke fatigue represents an emotional struggle. One user described being pleased with his progress yet was annoyed at himself for concentrating on his 'physical recovery' without taking his 'mental recovery'(SS8) into account. Included in his 'mental recovery' was the idea of 'bouts of fatigue' that 'knocked [him] for six'. Yet for others, overcoming the fatigue was considered part of the physical recovery from stroke. One survivor reported that 'apart from tiredness and intermittent vertigo the physical effects of a stroke . . . have thankfully passed'(SS14).

Summary

Table 1 includes fragments of quotes and paraphrasing of comments from the Talkstroke forum representative of our six themes.

Themes	Selected User Quotes & Paraphrased Discussion Points
Medicalisation of PSF	A man replied that he suffered from tiredness. (CG6) His consultant told him that tiredness is a major after effect of stroke. (SS9) She described tiredness to another user as a classic post stroke symptom. (SS30)
A fatigue unique to stroke	When reflecting on post-stroke fatigue, a man commented that he felt everybody seemed to suffer from tiredness following a stroke, further describing it as a silent disability that is not often talked about unless it is brought up in discussion. (SS8) When replying to other forum users, one woman described post-stroke fatigue as a stroke legacy. (SS12)One man told other users thathe knew his stroke caused the fatigue he experienced after. (SS36)
Acceptance and normalisation of PSF	One forum user used metaphor in a response to explain the length of time she believed fatigue may last for after a stroke, telling the user that fatigue is a guest you're stuck with and explaining that acceptance is important to be able to learn to live with it. (SS12) One man responded to a concerned forum user to assure them that their feelings were normal and all stroke survivors could relate to post stroke tiredness. (SS29) One stroke survivors husband reflected that his wife had learnt what the signs of tiredness were for her personally, and understood that they signal a need to rest. (CG5)
Fighting PSF	One male user highlighted that tiredness was a problem for him and he dealt with it by pushing onwards to fight the tiredness by keeping mentally and physically busy. (SS12) A woman replied that it was important to not give into the tiredness and to find strategies to combat it. (CG15) By related her tiredness to the brain injury, one user responded that it can be overcome and the brain can outwit the need for sleep. (SS9)

Survivors' biological explanations and beliefs	One care giver made sense of the tiredness by considering the tiredness as result of the brain damage caused by a stroke event. (CG9) A forum user wrote an affirmative response that the tiredness he often experienced was due to the brain healing. (SS17) A woman drew upon information she had been given by a medical professional that post-stroke fatigue occurs as a result of the brain being tired. (SS18) One woman personified her brain, responding by explaining that if the brain doesn't get tired, it will not have the rest time necessary to heal. (SS26)
How survivors cope with PSF	*A) Involving healthcare professionals* One man told other users that his consultant had signed him off work as unfit for the forseeable future. (SS9) Another forum user was told by her GP that tiredness was something she would have to get used to and it would improve with time. She reflected on this, writing that she needed to accept it was a part her now. (SS59) *B)* Her husband had been written off by therapists. She elaborated on this by saying they still said he had reached his full potential even after significant time has passed. (CG17) *C) Lifestyle changes* One forum user advised others that they needed to learn to live within their post stroke limitations and take it easy when needed. (SS39) A care giver reflected on her experiences and advised others that it was important to make plans to occupy their time, however if the tiredness became overwhelming to have a rest period. (CG24) *D) Mental vs. physical recovery* One forum user replied that he experienced bouts of fatigue. When describing how it felt, he used a figure of speech, saying that it knocked him for six. (Stroke Survivor, N14) A daughter responded that the tiredness was still a big problem for her mum but she reflected on the importance of her mum understanding her own capabilities to know what is and isn't manageable.(CG13) One man voiced frustration at concentrating on his physical recovery after the stroke more than his mental recovery when discussing his fatigue. (Stroke Survivor, N14)

Table 1. Themes based on exemplar quotes from the Talkstroke Forum archives. PSF = post-stroke fatigue. SS = Stroke Survivor. CG – Care Giver.

Discussion

For stroke survivors and their care-givers the forum provided legitimacy by acknowledging the existence of post-stroke fatigue, as well as offering management strategies based on lived experience. The homogeneity of forum users' interpretations of post-stroke fatigue is of particular note - the symptoms were repeatedly described as a 'legacy of stroke'(SS45), and the existence of post-stroke fatigue in this online community was rarely, if ever, questioned.

Forum users reported a number of conflicting approaches to managing fatigue with some patients being told by their healthcare providers to rest and others being given no information at all. Commonly included in such posts were quotes to the effect that post-stroke fatigue was 'not understood by the medical profession'(SS37). As a result, stroke survivors and care-givers would seek out and offer their own, often metaphorical, explanations. Understanding and defining fatigue in clinical settings has provided a challenge for many decades due to the complex interaction of biological, psychosocial and psychological elements, which makes understanding and management difficult for clinicians and patients alike[19]. The reported lack of medical consensus over approaches

to post-stroke fatigue reflects an absence of a standardised approach to post-stroke fatigue in the medical setting. ambiguity extends to understanding of how fatigue after stroke occurs and what factors influence its onset and longevity This also holds true in literature exploring fatigue management with Wu's 2015 Cochrane review being the only review to seek answers to whether any intervention reduces the proportion of people with fatigue, fatigue severity or both. Methodological quality was poor throughout and no studies included primarily studied the effect on post-stroke fatigue. Treatment modalities included pharmaceutical options such as fluoxetine, enerion and citicoline. Non-pharmaceutical options were a fatigue education programme, a mindfulness based stress reduction programme and continuous positive airway pressure (CPAP)[20].

Comparison to other literature

Post-stroke fatigue is reported as one of the largest unmet needs in stroke survivors[5]. Despite this, fatigue is only recently starting to be included within prominent clinical guidelines[21-24]. This is largely due to the lack of high-quality studies and methodological variation evident in the post-stroke fatigue literature[25]. In a report by the European Stroke Organisation on evidence-based stroke rehabilitation, although several topics are discussed, fatigue is noticeably missing[23]. The absence of guidance for clinicians working with this population is reflected in the absence of a standardised approach as was apparent in the online forum posts.

Analysis of online community content is arguably an under-used research design, despite being found to potentially offer additional insight to traditional interviews[16]. Other research utilising the TalkStroke forum archives have been found to compliment evidence collected employing other research designs[26]. Balasooriya-Smeekens' 2016 study found that residual impairments, including fatigue, affected stroke survivors' return to work. Forum users also discussed a multitude of other difficulties stemming from fatigue including feeling misunderstood and suffering from an 'invisible disability'[26]. Our analysis found forum users referred to fatigue in this way. Balasooriya-Smeekens' study also alluded to the frequency of individuals experiencing fatigue after a stroke event, with over half of the forum users posting about occupation difficulties also pinpointing fatigue as an important factor. Recent research has examined factors associated with post-stroke fatigue and found reduced independence in activities of daily living and higher anxiety levels had a direct association with level of fatigue[27].

Strengths and Limitations

This paper is the first to explore post-stroke fatigue from the perspective of stroke survivors and care-givers through an online forum. Previous qualitative studies have found online forums to constitute a rich and important data source, where patient perspectives are given in open discussion in the absence

of a researcher[16]. As such, the insights into post-stroke fatigue gathered in our study provide a useful and valid contribution to the understanding of this common and debilitating problem.

A further strength of this study is that it employed a 'naturalistic' data collection methodology[16]. Using an archived online forum means our data were created from natural interactions between fellow forum users, rather than from pre-defined or guided discussions with researchers, thus removing participant bias toward the research agenda[21]. Therefore, we believe that this approach has enabled us to best elicit understandings and approaches to post-stroke fatigue from the perspective of stroke survivors and their care-givers.

A potential limitation of this study is that forum users may not be typical of all stroke survivors. Participants tend to be younger and less severely affected by stroke[17, 21]. It is possible that the constructs of post-stroke fatigue derived from our analysis of the forum posts are only representative of the beliefs of a self-selecting group of forum users. Forum users may also not represent all social classes, as De Simoni and colleagues highlighted by identifying over half of posters as holding professional occupations[17]. However, this information was only gathered from a minority of users so should be considered with caution. Furthermore, the data collected was from archives dated before 2012. Qualitative research has been published since this date and so this may not represent current understanding of post-stroke fatigue. This is however, the most recent study investigating the topic within an online community.

By utilising a naturalistic data collection method, we were unable to identify the underlying cause of the fatigue that participants were discussing on the forum. Fatigue has been approached in this paper from a lay understanding, rather than from a 'medical model. There is a chance we were not able to exclude all forum posters under the age of 18 due to several participants having unknown age. The search terms utilised could also present a limitation, as Boolean operators were not used. Further qualitative research could incorporate a wider range of terms within the search strategy.

Implications

The array of conceptualisation and approaches to managing post-stroke fatigue identified in this analysis highlights the need for better evidence on how to optimise the recovery process for stroke survivors with fatigue and their care-givers. Our data suggest that some stroke patients use the on-line community of stroke survivors and care-givers to provide informal explanations and reassurance. The construct of PSF as a 'tiredness like no other' (SS6) that 'everybody seems to suffer with' (SS24) suggests a requirement for a consistent understanding and explanation to be provided by healthcare professionals, reducing the reliance of sufferers to seek informal explanations and reassurance from within the stroke community. Capturing the most prevalent beliefs, largely that fatigue is 'due to the brain healing' (SS17) enables assessment of the gap between clinical and community knowledge informing the education required to better inform survivors. Better understanding by health care professionals of these lay beliefs may help them support their patients.

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Figure Legends: Figure 1. Flowchart of process for data selection and analysis.

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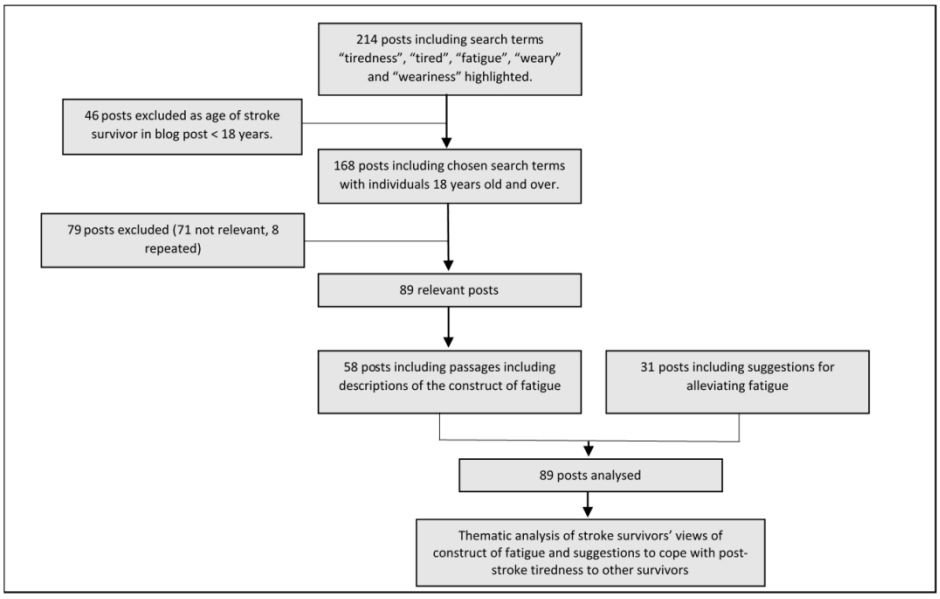

Figure 1. Flowchart of process for data selection and analysis.

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Reporting checklist for qualitative study.

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Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

	Reporting Item	Page Number
#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
#2	Summary of the key elements of the study using the abstract format of the intended publication; typically	2

		includes background, purpose, methods, results and conclusions	
Problem formulation	#3	Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	3-4
Purpose or research question	#4	Purpose of the study and specific objectives or questions	4
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.	4,9
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	10

Context	#7	Setting / site and salient contextual factors; rationale	2,4
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 saturation); rationale	4
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	4
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	4,5
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)	5
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and	5

		security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	5
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	5
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	5-8
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	5-8
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	8-9
Limitations	#19	Trustworthiness and limitations of findings	9
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were	10

		managed	
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	10