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Stroke survivors' experiences and perceptions of post stroke fatigue education in the subacute phase of stroke. The FASE qualitative study.

Abstract

Introduction

Post-stroke fatigue significantly impacts stroke survivors' rehabilitation, morbidity and quality of life. The evidence-base of post-stroke fatigue education is scarce and inconsistently translated to practice. Research is necessary to understand the current provision, impact and perceptions of post-stroke fatigue education from the stroke survivor's perspective. The aim of this study is to develop an understanding of stroke survivors' current experiences and perceptions of fatigue and the role of post-stroke fatigue education in subacute stroke.

Methods

A United Kingdom-based qualitative inquiry using semi-structured interviews involving 10 participants who had experienced subacute stroke was conducted using thematic data analysis.

Findings

The overarching theme of acceptance and adaptation reflected possible mechanisms in how stroke survivors manage post-stroke fatigue. Theme one highlighted the individual and diverse nature of post-stroke fatigue. Theme two, the variability of stroke survivors' current experiences, reflected variability in content and context of post-stroke fatigue education. Theme three, the role of stroke services, described perceived responsibility and ability of stroke services to provide post-stroke fatigue education.

Conclusions

Post-stroke fatigue education is variable in practice. The results suggest further investigation of a stroke pathway approach for post-stroke fatigue education, involving core aspects suitable for a spectrum of stroke survivors with additional components tailored to individual needs.

Introduction

Stroke is the fourth largest single cause of death in the UK and the leading cause of enduring disability (Stroke Association, 2018). Stroke is a serious life-threatening medical condition that happens when the blood supply to part of the brain is cut off, resulting in a variety of deficits depending on where the stroke occurs within the brain (Stroke Association, 2018). Approximately 100,000 strokes occur in the UK annually with a prevalence exceeding 1.2 million, resulting in a significant social and economic burden (Public Health England, 2018).

Post-stroke fatigue (PSF) is a common and debilitating condition with a prevalence of between 35% and 92% (Duncan, Wu & Mead, 2012). PSF is described as a subjective and disproportionate mental or physical exhaustion, not typically improved with rest and impacting on daily activities (Van Eijnsden *et al.*, 2012). PSF creates a significant barrier to rehabilitation in the subacute post stroke phase and is associated with reduced functional ability, quality of life and increased morbidity and mortality (Duncan, Wu & Mead, 2012). It was highlighted by 58.3% percent of stroke survivors as one of the most disabling symptoms of stroke (Van Eijnsden *et al.*, 2012). However, McKeivitt *et al.* (2011) identified 43% of stroke survivors surveyed (1251 participants) 1-5 years post stroke received inadequate support.

PSF has been identified as a research priority by stroke survivors, carers and clinicians (Pollock *et al.*, 2014). The multifaceted nature of PSF supports the need for complex educational interventions as a potentially useful management intervention (Wu *et al.*, 2017). This is particularly important in the subacute phase of stroke reflecting the most

significant period of rehabilitation and rate of recovery, defined as the first 6 months post stroke (Hidler *et al.*, 2009).

In 2016 the National Clinical Guidelines for Stroke expanded recommendations to include fatigue (Intercollegiate Stroke Working Party, 2016), involving assessment for physical and mental factors contributing to PSF when participation in rehabilitation and quality of life was affected. Provision of information and support to enable stroke survivors to identify triggers and develop fatigue management strategies was recommended. Although the guidelines highlighted the importance of addressing fatigue, the lack of detail has resulted in ambiguity of what to include, when and how to implement the recommendations.

To date, a limited number of small interventional studies of PSF education have been conducted as illustrated in Table 1.

Table 1. Studies of post stroke fatigue education.

Study, Author and study design	Inclusion/exclusion criteria	Intervention	Primary Outcome Findings
Clarke, Barker-Collo & Feigin (2012). Parallel block randomised trial	<p><u>Inclusion:</u> First Ischaemic or haemorrhagic stroke, stroke onset 3-18 months FSS >3.9, medically stable, able to travel to sessions.</p> <p><u>Exclusion criteria</u> MMSE < 23, agitation, medically unstable, unable to speak English, unable to travel, comorbidity impacting results.</p>	<p><u>Fatigue management group (FMG):</u> n= 9 Six 60 minutes weekly group psychoeducation sessions targeting fatigue.</p> <p><u>General education group (GE):</u> n= 7 Six 60 minutes weekly group general education sessions without targeting fatigue,</p>	<p>FSS at 6 weeks FMG- MD 1.2, GE - MD .19, SMD -.43, 95% CI -1.35 to .50, p=.02</p> <p>Between group comparison not significant FSS, FMG, MD,1.18, GE, MD .19, p=.086</p> <p>FSS at 3-month FMG-MD 1.2, GE – MD 0.54, p= .086</p>

<p>Zedlitz <i>et al.</i> (2012). Parallel block randomised trial</p>	<p><u>Inclusion criteria:</u> stroke > 4 months before recruitment, CIS-f \geq 40, 18 to 70 years old, able to walk independently.</p> <p><u>Exclusion criteria:</u> No cardiopulmonary complications, psychiatric disorders, cognitive impairment or depression</p>	<p><u>Cognitive intervention group (CO):</u> n= 45 2 hour sessions, once a week, for 12 weeks</p> <p><u>Combined CO and physical training (COGRAT):</u> n= 38 2 hour sessions and twice a week for 12 weeks including walking on treadmill, strength training, and home exercise.</p>	<p>CIS -f $p > .001$ and SOL-f $p = .007$ at 6 months.</p> <p>The most significant size effect was for CIS-f, CONGRAT, $n^2_p = .48$, SOL-f, $n^2_p = .12$</p> <p>At an Individual level more participants in CONGRAT group had a clinically relevant improvement on CIS-f , $X^2 = 9.63$, $p = .002$</p>
<p>Wu <i>et al.</i> (2017). Quasi experimental single armed feasibility study</p>	<p><u>Inclusion criteria:</u> Above 18 years, stroke 3-24 months prior, self-reported fatigue, recruited from Lothian in Scotland.</p> <p><u>Exclusion:</u> Severe depression, cognitive and communication impairment, medically unstable, living in nursing home, recruitment into other studies or receiving treatment for PSF or depression.</p>	<p>12 recruited and 8 completed intervention. Manualised individual psychological intervention, 6 one hourly sessions at two-week intervals. One month follow up booster telephone call.</p>	<p>Post treatment - FAS, MD 4.8, 95% CI 2.1-11.6, $p = .15$</p> <p>One month follow up FAS, MD 7, 95% CI .8 -14.8, $p = .07$</p> <p>Three months follow up. FAS, MD, 9.3, 95% CI 1.4-17.1, $p = .03$</p>
<p>Nguyen <i>et al.</i> (2017). Single centred randomised control trial</p>	<p><u>Inclusion Criteria:</u> 16-70 years, history of stroke, FSS \geq 4, poor sleep on Pittsburgh Sleep Quality Index >5</p> <p><u>Exclusion criteria:</u> Co-morbid neurological disorders, acute psychiatric symptoms or substance abuse. Night work or travel over last month. Sleep apnoea.</p>	<p><u>Experimental arm:</u> n=9 8 weeks of adapted CBT and 30 minutes of moderate exercise 3-5 times weekly advised.</p> <p><u>Control arm:</u> n=6 Waiting lists</p>	<p>Two months FSS, MD 1.74 CI of 95% 0.70 - 2.77, $n^2 = 0.52$</p> <p>Four months FSS, MD, 1.92, 95% CI 0.24 - 3.60, $n^2 = 0.36$</p>
<p>Johansson <i>et al.</i> (2012) Cross-over RCT design</p>	<p><u>Inclusion criteria</u> Ischaemic and haemorrhagic stroke, > 1 year after stroke, MFS \geq 10. 30 to 65 years old.</p>	<p><u>Treatment group:</u> (n=7) MBSR 2.5 hour sessions weekly for 8 weeks including gentle Hatha yoga, body scan and sitting meditation.</p>	<p>MFS, MD -1.01, 95% CI -2.08 to 0.6, $p = 0.008$ at eight weeks.</p>

	<u>Exclusion criteria</u> Significant co-morbidities, cognitive impairments	One day silent retreat between session 6 and 7. <u>Control group: (n= 9)</u> Waiting list control	
Hofer <i>et al.</i> (2014) Single armed quasi experimental study	<u>Inclusion criteria</u> Diagnosis of stroke <u>Exclusion criteria.</u> History of neurological disease. Chronic disabling pathologies, Progressive neurodegenerative illness. Language impairment	8 participants, Individual neuropsychological and psychotherapeutic interventions and post stroke fatigue rest management program. Length of sessions and duration of course individually tailored. Average session duration 50 minutes. Mean of 19 sessions over one year.	SQMF at 10 weeks no significant results identified. P value and CI not reported. From pre-test to follow up (duration variable 14-25 sessions) significant improvement SQfMF, MD 3.87, $p>.017$

FSS = Fatigue Severity Scale, CIS-f = Checklist of Individual Strength-fatigue, FMG= Fatigue Management Group, CBT= cognitive behavioural therapy, FAS = Fatigue Assessment Scale, CONGRAT = Cognitive and Graded Activity training, CO= cognitive, SOL-f = Self Observational List-fatigue, SQMF= Self- Assessment Questionnaire for Mental Fatigue, MD = Mean deviation, CI= confidence interval, p = probability value, r = correlation coefficient, f =variation between sample means. MMSE= Mini Mental State Exam, SOL-f = Self Observation List-fatigue, n^2 = effect size, MBSR = Mindfulness Based Stress Reduction, MFS = Mental Fatigue Scale.

However, the studies had heterogeneity in design, implementation, outcomes and results (Wu *et al.*, 2015). The Cochrane systematic review (Wu *et al.*, 2015) concluded that there was insufficient evidence of the efficacy of any fatigue management intervention, including PSF education, but considered psychological approaches feasible in combination or separate to activity (Table 2).

Table 2. Cochrane systematic review (Wu *et al.*, 2015).

Study	Criteria	Number and types of studies reviewed	Primary Outcome
Cochrane systematic review included in literature review (Wu <i>et al.</i> , 2015)	RCTs with interventions used to treat, prevent PSF or measured PSF as a secondary outcome. Clinical diagnosis of stroke Over 18 yrs. Stroke or mixed populations with 75% of stroke or separate data for stroke. Only data from first phase of cross over designs used.	12 trials including 703 participants. 8 trials assessing efficacy of PSF treatment, 7 suitable for meta- analysis (5 pharmacological, 2 non-pharmacological). 4 studies not primarily investigating fatigue but reported as secondary outcome measure	Insufficient evidence to support use of any intervention to treat PSF. Meta- analysis - fatigue severity lower in intervention compared to control group (244 participants, pooled SMD -1.07, 95% CI -1.93 to -0.21) with significant heterogeneity (I^2 , 87%, df 2, $p < 0.00001$). Significance not maintained in trials with adequate blinding and allocation concealment. PSF Education non-significant on subgroup analysis.

RCT= Randomised control trial, PSF= Post Stroke Fatigue, SMD= Standard Mean deviation, CI = confidence interval, df = degrees of freedom, I^2 = level of heterogeneity in sample.

The review recommended further robust evaluation but due to limited evidence available it provided little in terms of recommendations to assist clinical practice resulting in uncertainty and continued inconsistent PSF education provision (Drummond *et al.*, 2017).

Involvement of stroke survivors is central to the development of interventions that are responsive, effective and acceptable, as advocated by the Guidelines for Developing and Evaluating Complex Interventions (Craig *et al.*, 2008). This is particularly important considering the subjective nature of fatigue (White *et al.*, 2012). However, there is a paucity of studies specifically exploring stroke survivors' current experience and perceptions of PSF education to understand the acceptability and efficacy of

current education and the development of new interventions. PSF significantly affects stroke survivors' occupational performance, roles and routines, therefore as occupational therapists it is important to understand PSF, its impacts and the interventions that optimise stroke survivors' occupational engagement and mastery (Flinn and Stube, 2010).

Aims

The aim of the Fatigue After Stroke Education (FASE) study is to develop an understanding of stroke survivors' current experiences and perceptions of fatigue and the role of PSF education in the subacute phase of stroke.

Method

Design

A general qualitative inquiry design was selected to develop a rich and holistic understanding of participants perceptions and experiences of PSF education (Creswell, 2014). A pragmatic epistemology was used to enable practical actionable answers to real-life problems, exploring the ambiguity of stroke survivors' experience of PSF education and perceptions of its development (Feilzer, 2009). A critical realism ontology compatible with pragmatism, provided a philosophical framework promoting critical consideration experiences and perceptions of PSF and exploring potential causal mechanisms which generate these. This was relevant to the complex aetiology of PSF highlighted by Wu *et al.*, (2015) involving consideration of physical symptoms, participants thoughts, actions, beliefs, and social dynamics. Exploring the underlying

mechanisms and contexts promoted by critical realism were also key to understanding how, why and under what circumstances PSF education could benefit stroke survivors (Wilson *et al.*, 2015).

Participants

Ten participants were recruited from a single site in the South West of England via the Stroke Association, commissioned to review all stroke survivors discharged from local inpatient stroke units. Stroke survivors were recruited between one and six months after diagnosis. They were eligible for recruitment into the study if they were diagnosed with a stroke, self-reported fatigue and had capacity to consent. Potential participants were excluded if they experienced co-morbidities where fatigue can be a major problem, for example multiple sclerosis and chronic fatigue syndrome. An inability to comprehend and express language at a paragraph level was also an exclusion criterion, as the level of communication would not enable the depth and richness of information required to meet the aims of the study.

Sampling

Purposive sampling was used to obtain information-rich participants (Creswell, 2014), sampling the characteristics of age, gender, stroke diagnosis and socio-economic backgrounds. However, as only a single recruitment site was used, an element of convenience sampling needs to be acknowledged. Maximum variation was selected to reflect the diversity of stroke survivors (Suri, 2011) and to enable insight into the variety of experiences and perceptions of PSF education. A sample size of ten was

determined by resource capacity and therefore data saturation may not have been achieved.

Patient and public participation (PPI)

A PPI consultation of the FASE study was conducted in the design phase. This involved discussions with three participants who were asked to review the study proposal, clarity and relevance of participant information, considerations for interviewing and methods of dissemination. The key findings of the PPI included broadening and contextualising terms of fatigue, rewording questions regarding coping strategies used by stroke survivors and increasing prompts to look at timing and context of education. Also highlighted by these discussions was the need for grading communication to participants needs, developing a collaborative and empathetic researcher-participant relationship and ensuring robust support service to minimise psychological distress and fatigue. The feedback informed development of the pilot interview schedule.

Procedure

The study received ethical approval from University Faculty of Health and Human Sciences and Schools of Medicine and Dentistry Student Ethics Committee (2018) and the Stroke Association National Research Department. Stroke Association Coordinators used a maximum variation matrix (characteristics included diagnosis, age, gender and post stroke impairments) to identify stroke survivors who met the eligibility criteria. They provided potential participants with a participant information sheet and discussed the study using a protocol to avoid coercion. Verbal consent for the

researcher to contact interested participants via telephone was also gained by the Stroke Association Co-ordinators, after which the researcher contacted potential participants by telephone to discuss and check their understanding of the study. An interview was arranged at a convenient venue and time for the participant and an appointment letter sent detailing these arrangements. Participants were re-contacted on the morning of the interview to ensure suitability, due to the variable severity of PSF, as highlighted by the PPI consultation. Face to face written consent was obtained prior to interview.

Data collection

Data was collected via one-to-one face-to-face semi-structured interviews by the principle investigator who had training in qualitative interviewing. This provided flexibility to pursue ideas and elaborate on pertinent information which may not have been previously considered. Furthermore, individual interviews enabled grading of the structure, timing and duration of interviews to suit participants within this sample. An interview schedule including a pictorial support version was developed based on a culmination of resources, namely: an analysis of previous PSF studies, speech and language therapist advice and feedback from the PPI consultation. The interview schedule was piloted to ensure the questions were appropriate and generated adequate answers. No modifications were identified as being necessary and hence data from the participants who engaged in the pilot interview were included in the sample.

Data analysis

An inductive thematic analysis using Braun & Clarke's (2006) six step process was used to provide a systematic and flexible method of data analysis. This approach searched for significant and dominant patterns rooted within the data.

The lead researcher immersed herself in the data (transcriptions from the audio recordings and field notes) by actively reading the data and noting initial ideas of interest. Data were systematically searched to generate initial codes. This process was completed using NVivo 11.4.2 (QSR International Pty Ltd., version 11.4.2, 2016). Codes were sorted into potential themes by the principle investigator. Coding was then independently reviewed by two other researchers of differing professional backgrounds, with any discrepancies discussed to obtain consensus.

Themes were reviewed by the research team both at the level of codes and as an entire data set to refine and define the essence of each theme in relation to the aims of the study. Member checking was conducted once themes were generated. Seven participants provided member checking and whilst there were no significant changes to the themes identified, suggestions were made to subthemes within the themes.

Ensuring rigor and reflexivity

The study was reported in accordance to the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong, Sainsbury & Craig, 2007). Credibility was enhanced through member checking ensuring the findings reflected participant perceptions (Hadi, 2016). Field notes were used to support the findings and capture contextual factors. Dependability and confirmability were addressed within data analysis. Two independent researchers provided peer review triangulation with field notes used in cross comparison (Hadi, 2016). Throughout the study a reflexivity diary

was kept to acknowledge and separate the researcher's views, in order ensure the findings were emergent from the data (Creswell, 2014).

Results

Sample demographics

The sample (n=10) contained appropriate proportions of gender (six females, four males) and ratio of ischaemic (n=9) and haemorrhagic stroke (n=1) to reflect the diversity of the national stroke population (Stroke Association, 2018). There was limited ethnic diversity due to the nature of the local population. There was heterogeneity in age (31-83 years, mean 65 years), stroke diagnoses, self-reported post stroke impairments, occupational and social backgrounds (Table 3).

Table 3. FASE Study Participant Demographics.

Participant Synonym	Gender	Age	Diagnosis	Post stroke impairments				Occupation	Social situation
				Motor	Sensory	Cognitive	Language		
1. Sarah	Female	62	Left PACI	N	N	Y	Y	Housewife	Lives with husband and son. No carers
2. Paul	Male	83	Right PACI	Y	Y	N	N	Retired engineer	Lives with wife and son. Care recently stopped.
3. Holly	Female	81	Right LACI	N	N	N	N	Retired care manager	Main carer for husband.
4. Alice	Female	51	Multiple ischaemic strokes	Y	Y	Y	N	Housewife	Lives with husband and two grown up children, no care package.
5. Scott	Male	47	Left TACI	Y	Y	Y	Y	Full time employment in garage	Lives with wife, works full time.
6. Tracey	Female	72	Right PACI	Y	Y	Y	Y	Retired Bed and Breakfast manager	Lives alone. Limited family support.
7. Agnes	Female	68	Right PACI	Y	N	N	Y	Retired from food factory	Lives with partner. Partner working part time.
8. George	Male	75	Right PACI	Y	N	Y	N	Retired plaster and decorator	Lives alone in flat with care package.
9. Martha	Female	77	Right Haemorrhagic stroke	Y	Y	N	N	Retired nurse	Husband is main carer and package of care in situ.
10. Harry	Male	31	Bilateral POCI	Y	Y	N	Y	Shop Retailer	Previously living alone,

									currently with grandparents.
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PACI = Partial Anterior Circulation Infarct, LACI = Lacunar Infarct, TACI= Total Anterior Circulation Infarct, POCI = Posterior Circulation Infarct, Y = Yes, N = No .

Themes

Three themes and one overarching theme addressing the aims of the study were formulated reflecting the essence of the data:

- The individual and diverse nature of fatigue
- Variability of stroke survivor experience of PSF education
- The role of stroke services

The overarching theme, acceptance and adaptation was present throughout the data and will be discussed first.

Overarching theme of acceptance and adaptation

Acceptance and adaptation were identified as a significant overarching and repeating theme throughout the data. It was suggested as a method for how stroke survivors cope with PSF and advocated as an aim for PSF education to help stroke survivors self-manage fatigue and meet their potential. Acceptance was defined as the ability to accept intrinsic worth, despite disability in order to attain psychological adjustment (Dembo, Leviton & Wright, 1956). Adaptation was the process of making positive adjustments to new conditions (Townsend *et al.*, 2010).

“I think the main thing is accepting what happened because unless you accept it you can’t necessarily deal with it and move on from it.” (Harry, line 405-407)

The data highlighted that the participants varied substantially in their personal reactions to PSF with differing levels of acceptance and adaptation.

“At the moment we have had to make some changes and we have accepted it, but it’s part of getting better.” (Paul, line 248-250)

“It’s too much and I just give up. I think just don’t bother it’s easier.” (Tracey, line 53)

Participants described how the opportunity to discuss and understand PSF with health professionals enhanced their acceptance of the condition.

“By talking about it, it makes it clearer. You understand it more and accepting it more as well.” (Harry, line 372-373)

The participant’s comments suggested that poor acceptance reduced coping, increase psychological distress and low mood.

“I struggle to accept this. It looks like there’s nothing wrong, but it upsets me and I just have to carry on.” (Holly, line 36-37).

Flexibility, problem solving and adjustment of strategies to accommodate changes in PSF was suggested to improve adaptability and an important part of experiential learning.

“Me and the wife have just adjusted to it and changed our priorities and expectations a bit, just change our activities and rest as we need. It’s about keeping flexible.” (Paul, line 144-150)

Acceptance and adaptation appear to vary considerably indicating the need for individual assessment and tailoring of education.

“You need to keep going to get your life back. You need to set yourself goals.” (Scott, line 216-221)

“I get very tired, lazy, don’t do nothing, just sit in this chair and doze like, on and off. Sometimes all-day long. Just don’t have the energy.” (Tracey, line 28-31)

The individual and diverse nature of fatigue

PSF was frequently referred to as a new and sudden onset of overwhelming tiredness. Participants consistently described perception of insufficient energy, reduced tolerance of external stimuli, necessity to sleep and having to limit or cease activity because of fatigue. Beyond this, the individual and diverse nature of PSF was reflected by the participants varied responses about fatigue, the impact on stroke survivors, symptoms, severity, patterns and triggers of fatigue.

“Like I say tiredness affects me physically. It makes my movement a lot harder and with the standing (pause) it can make me more wobbly when I’m tired.”

(Martha, line 110-112)

“If I am tired I know my speech and swallow will be worse so I have to concentrate more.” (George, line 135-138)

“I don’t really get physically tired, for me it’s mostly mental.” (Harry, line 123)

There was also diversity in the severity psychological impact with some experiencing minimal changes in mood, whilst others identified significant changes to mood, self-identity and locus of control. The impact of participation in activity, roles and routines varied with occupational demands, social support, participant and family understanding of PSF suggested as possible factors.

“Whereas before I could keep going, ran the house ... not now, family have to help me... putting more on them and feeling a bit useless.” (Sarah, line 77-80)

“I can’t go out so much in the evenings as I get too tired... or do the social things like going out with mates.” (Scott, line 115-118)

Predictability of fatigue was closely linked to understanding the causes and triggers for PSF. This was challenging, however, because of the significant variability in the onset, timing, duration and severity of PSF throughout the day and during the subacute stroke period. For some participants there were patterns with clear triggers, whilst others reported constant or unpredictable PSF with insufficient warning signs.

“I would say the more I’ve done the quicker it maybe comes on.” (Harry, line 138)

“Often it comes unannounced (pause). You’re doing things and just suddenly you’ve got to stop. It’s like I’ve lost control.” (Holly, line 66-67)

Participants described PSF as an invisible disability in comparison to many other residual stroke symptoms.

*“Because they can’t see it they don’t understand and think I’m being a bit lazy.”
(Sarah, line 99)*

Participants highlighted the importance of understanding the individual and diverse nature of fatigue to help preparedness, visibility to others and acceptance through education.

The variability of stroke survivor experience of PSF education

Most participants discussed receiving some PSF education. Where PSF education was described by participants, there were commonalities, including provision of information about pre-warning of fatigue, potential causes, impacts and the necessity to modify expectations either verbally or via written information.

“The information explained the tiredness, understanding why I was tired. That it will get better but I’ll need to do things differently for a while.” (Martha, line 318-322)

“One of the occupational therapists said “you know you might get these periods where you’re shattered and you just have to give in to it”. From day one I rested.” (Alice, line 238-244)

Practical strategies described by six of the study participants included goal setting, promotion of activity, development or adjustment of existing routines and activity adaptation. However, when and how these were discussed, and level of support provided to implement strategies varied across the sample.

“In hospital they helped me if I got too tired, they gave me strategies. They just structured my day and helped me pace myself.” (Alice, line 521-523)

“It was the Stroke Association, they gave me general advice on how to do certain activities that helped.” (Paul, line 318-320)

“The therapist is working on getting me back into a routine, shows me a way of making things more simple... monitoring my tiredness and resting.” (Martha, line 67-69)

“They warned me of the tiredness but it was quite quick and just a warning really.” (Holly, line 354-355)

Participants described variability in the content, location, timing post stroke and services involved in providing PSF education. Some participants suggested education did not link to individual needs and insufficiently addressed coping strategies, especially immediately prior and after discharge home.

“The leaflet gives a bit more information but a lot doesn’t really apply to me or my situation and doesn’t help me cope with it.” (Holly, line 356-357)

“They didn’t tell me anything about it in the hospital. The only person who talked to me about it was the Stroke Association.” (Paul, line 318-319)

The environmental and social context of support was suggested as a key factor in determining the level of need and potential effectiveness of PSF education.

“When I came home there was no way I could cope. I just had to rest and my family were brilliant and I didn’t need much more support.” (Alice, line 82-89)

“It would have been good for them to organise a bit of help before I came home and having someone here to look at my home.” (Tracey, line 251- 256)

Some participants found the hospital environment too overwhelming or at an inappropriate time in their recovery to use the information. There was general consensus of the necessity and value of PSF education early within the context of the individual's home environment to aid recovery.

"In hospital, they did explain but I didn't really seem to take it in. I've understood a lot more since I've come home which is important at the start to help me get better." (Harry, line 327-334)

Participants perceived barriers to the provision of PSF education, particularly within the hospital environment. This included time availability, staffing, differing priorities from health professionals and the invisibility of PSF.

"It needs to be looked at and treated like all my other symptoms, given equal attention." (Scott, line 403-405)

"Apart from stroke Association no one else has seen me. I think if I was really bad and couldn't keep my eyes open maybe then they would have done more to help improve how I was feeling." (Sarah, line 293-300)

Furthermore, participants highlighted that cognitive and/or communication impairment post-stroke inhibited the effectiveness of PSF education provided.

“With my memory they can’t just give me loads of stuff. They got to show me in a way that makes sense otherwise it’s no use.” (George, line 226-269)

The impact of a lack of PSF education or appropriate grading of the content to individual need was suggested to have a negative impact on rehabilitation, functional abilities and participant and carer wellbeing.

“I think they should have discussed tiredness with us in a way we could understand and plan for it, rather than wonder why everything seemed really hard.” (Martha, line 338-341)

“It was just me and my partner and we didn’t know what to expect. I didn’t feel as safe and when (name of partner) saw how tired I was he was a bit worried of how we were going to manage.” (Tracey, line 251-253)

Tailoring the content, time and context of PSF education according to an individual’s needs and abilities were considered key to providing a positive experience.

The role of stroke services

Participants uniformly described a professional responsibility for stroke services to provide PSF education throughout their stroke journey.

“I think it’s their job to help get us better, back to normal.” (Sarah, line 287-288)

“Having all of the people within stroke all working together.” (Martha, line 397-398)

Participants highlighted suggestions through their experience of PSF education and their own experiential learning. With regard to the participants' perceptions of PSF educational development, there was consistency among processes, topics and strategies suggested across the sample. The findings suggest the provision of elements of fatigue education suitable for a range of stroke survivors. This core education was suggested to include assessment and setting goals to manage PSF.

"I think it should be part of the routine assessments and visits throughout your recovery." (Paul, line 413-414)

"Almost goals like you've had with your physical rehabilitation." (Scott, line 335)

There was commonality in suggested topics, for example, the individual and diverse nature of PSF discussed in theme one was a suggested topic.

"It's looking at what makes different people tired, what their triggers are really."
(Harry, line 505-506)

Information about stroke support services to enable an appropriate point of contact, clarity on their role in supporting PSF and family education were additionally proposed.

“They (professionals) should involve families. If they know how to support you and it makes that adjustment a bit easier.” (Martha, line 410-412)

Participants suggested core strategies to manage PSF including planning, prioritising, developing a routine, sleep hygiene and energy conservation incorporating simple activity adaptation, pacing and rest.

“Resting is really important and explain some of the problems if you push yourself too hard. Looking at sleep is good too...It’s making sure you get into a routine, doing a bit and resting.” (Agnes, line 438-443)

There was significant variability in consideration of other topics and strategies to be included in PSF education which were not consistent among the participants. This was dependent on the presentation of the participant’s PSF, current coping skills and their individual context, indicating the need for tailoring:

“There are some things we all need to know, but other things are different. I find physical things tire me out, but for my friend it was thinking more, so she would need different things from me.” (Martha, line 475-480)

Suggested topics included cognition, communication, nutrition, mobility, mood, increasing activity, environmental modifications, relaxation and activity specific strategies. Tailoring of specific strategies, mode, format and timing of education according to individual need was also strongly advocated.

“Other people may need more support, things written down, different things to be addressed when problems come up. It needs to be flexible to help them cope.” (Paul, line 539-543).

Participants suggested consistent and tailored PSF education would have multiple benefits. These included enhancing their understanding, adjustment of expectations and implementation of strategies to increase confidence in self-management, improve rehabilitation outcomes, resumption of valued roles and quality of life.

“You know what to do if you get stuck. It also motivates you, gives you goals to be motivated to do more, like dancing again.” (Paul, line 408-410)

Furthermore, incorporation of family members or significant others was indicated to facilitate awareness, dialogue, empathy and carers preparedness reducing current carer burden.

“Knowledge is power. If she (wife) knew what stroke victims are going through that would have helped our relationship.” (Scott, line 358-360)

Discussion/ implications

PSF is a prevalent and debilitating condition, highlighted as a research priority (Pollock *et al.*, 2014). Education is fundamental to address this (Duncan, Wu & Mead, 2012). Of note, this is the first known study to primarily explore PSF educational experiences

within the subacute phase of stroke. The results of the FASE study supported existing findings of variable PSF education (Eilersten, Omstad & Kirkevold., 2013; Kirkevold *et al.*, 2012). This was especially pertinent at transition points in the stroke pathway, particularly discharge home where either education during hospital admission or early on within the home environment was advocated, resonating with the themes in qualitative studies identified by White *et al.* (2012) and Eilersten, Omstad & Kirkevold. (2013).

The FASE study has a number of implications for stroke services. Participants uniformly described a professional responsibility for stroke services to provide PSF education, echoed in the recommendations of White *et al.* (2012) and the Intercollegiate Stroke Working Party, (2016). That said, PSF is not currently covered within the Stroke Specific Educational Framework (Stroke-education, 2018). Therefore, further research into the capacity of existing stroke services to provide PSF education and the development of additional fatigue stroke competencies and guidance would be advantageous.

Acceptance and adaptation were suggested as possible mechanisms by which stroke survivors cope with PSF and highlighted as a possible aim of PSF education. This is in line with the findings of qualitative studies exploring PSF experience, wherein acceptance and adaption were highlighted as predominant themes (Eilersten, Omstad & Kirkevold., 2013) and a key indicator of the ability to cope with PSF (Kirkevold *et al.*, 2012). Provision of education to facilitate knowledge and understanding is recommended to enhance acceptance (White *et al.*, 2012; Drummond *et al.*, 2017).

The findings of the FASE study support this and highlight the importance of assessing and supporting stroke survivor's acceptance and adaptation within PSF education.

Core elements of PSF were identified by participants, appearing to be independent of participant's context. These elements therefore have potential transferability for PSF education across the stroke population (Eilersten, Omstad & Kirkevold., 2013). Core education was suggested to include goal setting, increasing the stroke survivor's understanding of PSF, processes to monitor fatigue and support to implement and review strategies over time. This was consistent with recommendations from qualitative studies of PSF (Drummond *et al.*, 2017; Eilersten, Omstad & Kirkevold., 2013) and comparable with wider stroke educational recommendations (Cameron *et al.*, 2013). However, this study adds to a greater understanding of the importance of involving families which requires further investigation. The suggested core PSF strategies included planning, prioritising, developing a routine, sleep hygiene and energy conservation including simple activity adaptation, pacing and rest. These strategies addressed common aspects of fatigue across the diversity (Eilersten, Omstad & Kirkevold., 2013) and is typically incorporated within the few existing interventional studies of PSF education (Wu *et al.*, 2015).

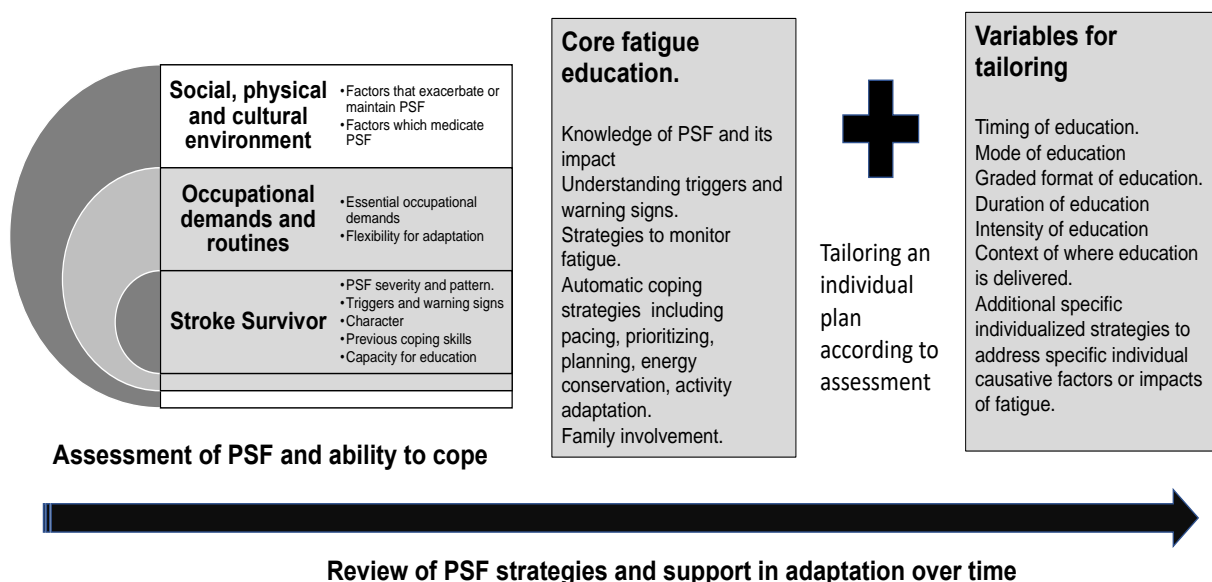
In addition, tailoring PSF education to reflect the individual and diverse nature of fatigue including strategies to address specific triggers or impacts according to stroke survivor's specific activities, routines and occupational roles is widely supported by existing qualitative studies of PSF to increase applicability (Drummond *et al.*, 2017; Eilersten, Omstad & Kirkevold., 2013). Furthermore, participants identified a need to tailor timing, duration, intensity, mode and format of PSF education according to

individual need reflected in wider studies of patient stroke education (Cameron *et al.*, 2013) and the NICE clinical guidelines for Stroke Rehabilitation in Adults (CG162, NICE, 2013).

A whole systems approach was suggested, involving delivery of PSF education across the stroke pathway. Such an approach included detailed early and ongoing assessment of PSF and core education across the stroke diversity. However, tailoring of specific strategies, mode, format and timing of education according to individual need was also strongly advocated as illustrated in Figure 1.

Figure 1. Recommendations for Post Stroke Fatigue education from the stroke survivor’s perspective.

PSF Education Recommendations



Methodological considerations

The strengths of this FASE study lie in its use of PPI and implementation of the COREQ guidelines for reporting qualitative research (Tong, Sainsbury & Craig, 2007) increasing transparency, dependability and transferability (Suri, 2011). The interview schedule was piloted to ensure questions generated appropriate responses to address the research aim. A reflective diary was used to acknowledge and separate the researcher's views with researcher triangulation to ensure the findings were grounded in the data obtained (Creswell, 2014). Member checking was completed by seven of the ten participants enhancing credibility.

The FASE study had several limitations. Stroke services vary geographically in terms of configuration, nature of services offered and specific contextual issues. Only one geographical and organisational recruitment source was used for the study, therefore the findings may have limited transferability within a different service context. All participants were sub-acute and residing within a home environment. Although there was heterogeneity in stroke severity, transferability of findings to stroke survivors in residential or nursing home settings and within the chronic phase of stroke may be limited, requiring further investigation. Furthermore, there was limited ethnic and cultural diversity within the sample potentially impacting on transferability and requiring further research (Creswell, 2014). The study findings only represent stroke survivor perspectives. Obtaining other stakeholder perspectives would further inform PSF education recommendations. Participants were interviewed regarding their experience of PSF education over the subacute period (first six months) and may have experienced recall bias. Furthermore, participants were excluded where moderate to severe cognitive and language impairment prohibited capacity or ability to communicate at a paragraph level. The experience and perception of PSF education maybe different within this cohort of stroke survivors and requires further

investigation. Finally, data saturation was not clearly established. Therefore, increasing sample size to a point of saturation would add rigor to this study (Van Rijnsoever, 2017).

Conclusions

The aim of the FASE study was to develop an understanding of stroke survivors' experiences and perceptions of PSF education in the subacute phase of stroke. Three themes; the individual and diverse nature of PSF, variability of stroke survivor experience of PSF education and the role of stroke services were formulated with an overarching theme of acceptance and adaption. The findings of this study are preliminary and could inform future research in order to develop a feasible and acceptable PSF educational package suitable for the stroke survivors within the subacute phase of stroke.

Key findings:

- PSF education is variable in content and timing.
- Core PSF education is recommended, suitable for the stroke diversity.
- Additional tailoring of PSF education according to individual assessment is required.

What this paper adds:

Integrating PSF education throughout the stroke pathway is required, involving core aspects suitable but with specific tailoring around the needs of the stroke survivor.

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