The FASE Study
(Fatigue After Stroke Education)

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Aims

Understanding fatigue from a stroke survivors’ perspective

Stroke survivors’ current experience of fatigue education

Stroke survivors’ perceptions of what fatigue education could include
Rationale for study

- Barrier to rehabilitation \(^1, 2, 3\)
- Prevalence of fatigue \(^1, 4, 5\)
- Significance of fatigue \(^6, 7\)
- Mortality and morbidity \(^4, 7, 8, 9, 10\)
Evidence base and Guidelines

Evidence base \(^{12,13,14,15}\)

RCP Stroke Guidelines \(^{16}\)

Inconsistency in education \(^{7,17,18,19,20,21}\)
Data collection and analysis

Face to face interviews of 10 stroke survivors

Thematic analysis

Implications for practice
Themes

Overarching Theme

Acceptability and adaptability

Theme

The individual and diverse nature of fatigue

Variability of stroke survivor education

The role of stroke services
Acceptability and adaptability

Mechanism of how stroke survivors cope with PSF

“I think the main thing is accepting what happened because unless you accept it you can’t necessarily deal with it. By talking about fatigue it makes it clearer. You understand and accepting it more.”

Acceptability definition

Adaptability definition
Variability of acceptance and adaptability

“At the moment we have had to make some changes and we have accepted it.”

“It’s too much and I just give up. I think just don’t bother - it’s easier.”
Factors affecting acceptability and adaptability

Invisibility and legitimacy

Knowledge and acknowledgement of PSF

Coping skills

Values and beliefs - Self expectation

Previous coping strategies

Adjustment of role/responsibilities

Family and carers support

Expectations of others
The individual and diverse nature of fatigue
Interactive nature of fatigue

“Everything has become harder and takes a lot more effort like the walking, talking and thinking. It just tires me out and makes everything worse, like when I’m tired the walking, talking and thinking is worse. It all interacts”.
Participant Quotes

“Where as before I could keep going, ran the house and everything... not now, family have to help me... and that's hard... having to ask for help... putting more on them and feeling a bit useless.”

“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 as I can never last long enough.”

“You’re angry inside that you’re not the person you were and momentarily you wonder if you’re ever going to be back completely as you were before this happened or whether this is going to go on.”
Variability of education

Assessment

Nature and consistency of education provided

Participant quotes

“Stroke Association gave me information. It’s helped me by telling me that it’s normal, that’s a big part of it.”

“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.”

“They warned me but it was quite quick and just a warning really. The leaflet gives a bit more information and some general tips but a lot doesn’t really apply to me or my situation and doesn’t help me cope with it.”
Variability of education

Lack of education within hospital

Acknowledgement by MDT.

“I was getting on well at the hospital and then suddenly I was at home and I didn’t know what to do. When you come out of hospital, nobody’s been or anything”

“I think they should have discussed tiredness with us and that it might be a problem, so we could understand and plan for it, rather than not know and wonder why everything seemed really hard.”
The role of stroke services

- Stroke services responsibility
- Staff training and education
- A team approach
- Sufficient staffing

“Having all of the people within stroke all working together.”
What do Stroke Survivors recommend?

Assessment and goal setting

- Core fatigue education
- Tailoring of education

Review of strategies and support over time
# Fatigue Assessment

## Social, physical and cultural environment
- Factors that exacerbate or maintain fatigue
- Factors which mediate fatigue

## Occupational demands and routines
- Essential occupational demands
- Flexibility for adaptation

## Stroke survivor
- Fatigue severity and pattern.
- Triggers and warning signs
- Character
- Previous coping skills
- Capacity for education
Core fatigue education

- Knowledge of fatigue
- Impact of fatigue
- Triggers and warning signs
- Strategies to monitor fatigue
- Family education
Core fatigue strategies

- Planning
- Pacing
- Prioritizing
- Energy conservation
- Graded activity
- Sleep hygiene
Tailoring of education

- Timing
- Varying verbal, written and practical support
- Format
- Duration
- Intensity
- Context
- Individualized strategies
Future Study

- Increase sample and sites
- Clinician and carer perspectives of fatigue education
- Develop a model of fatigue education
- Feasibility trial of PSF education
Questions

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References


