

Dragon's Den Research Proposal to ICPV by Julia Day

Friday 3rd May 2013 - Glasgow

Fatigue in Patients with Gliomas: Prevalence, Severity and Association with Sleep Disturbance, Cognition, Depression and Treatment.

Julia Day presented an outline of the proposal explaining that fatigue refers to abnormal tiredness that negatively impacts on daily functioning, that may vary in severity or pattern and does not improve with sleep. It can incorporate psychological, physical and mental components that can affect patients in different ways.

Moderate to severe levels of fatigue have been reported in 40-70% of patients with brain tumours throughout the illness which has been found to be significantly correlated with decreased quality of life.

The research proposal aims to assess the prevalence and severity of fatigue, and related factors recruiting participants from Edinburgh Centre of Neuro-oncology outpatient clinic at the Western General Hospital. The study will also see if poor sleep, and cognitive abilities are affected by fatigue.

The participants will be asked to complete the following tests: questionnaire on education, occupation and seizure history; a brief fatigue inventory; Hopkin's Verbal Learning Test (immediate word recall); Controlled Word Association Test (word generation); Test of Premorbid Functioning (reading aloud words); Trails A and B (connecting circles in a sequence); Hospital Anxiety and Depression Scale; Hopkin's Verbal Learning test (delayed word recall); timed 10 metre walk and Expanded Disability Status Scale (physical function assessment); Actigraphy watch to wear; Sleep log.

A relative or partner will also be asked to complete a questionnaire relating to changes in the patient's day-to-day functioning.

It was explained that complete participation for the trial would be carried out over 2 visits at a convenient time and place for the participant either at the clinic or at home.

The members of ICPC felt that too much information was being requested, and that this information should not be collected in a hospital but should be done at the patient's home. It was thought that the patients would feel more in control at home.

There was genuine concern that too many tests were being requested. One member (who suffers from chronic fatigue) said that she would find it mentally exhausting to complete so many tests.

It was suggested that the tests could be broken down into different sessions and that the patient needed to be interviewed in a quiet room that had a bed so that the patient could rest if necessary.

There was some concern over the wording in the proposal of "cognitive failures". It was thought that this should be re-worded to say cognitive issues rather than failures.

It was thought that there should be some questions relating to issues with sexuality even though it was understood that the study was measuring fatigue.

There was a discussion regarding the involvement of a relative. The study participant needed to be asked in private if a relative could be approached. It was felt that this needed to be handled carefully, as some participants would not feel comfortable being asked in front of a relative.

It was agreed that the actigraphy watch was a good idea as it involved very little effort on the patient's behalf.

It was agreed that social isolation was a major issue for patients suffering from fatigue and it was felt that it was a good thing to be asked to be involved in research. Patients do want more research on this particular subject.

It was suggested that any participant should receive a letter of thanks for taking part in the research.

Lesley Turner
Independent Cancer Patients' Voice
13th May 2013