What are the experiences of people recently diagnosed with non-epileptic attacks and referred to an information and self-help website?

Rebeca Mayor
2014 Cohort
Service Related Project
Presentation Aims

- Background
- Rationale for project
- Service context
- Method
- Progress so far
- Reflections
Background

What are non-epileptic attacks?

- Nonepileptic attacks (NEAs) appear similar to epileptic seizures but are not associated with abnormal electrical activity within the brain (Reuber, 2008). There is no single accepted theoretical model of NEAs but it is generally considered that both biological and psychosocial factors are involved (Reuber, 2009).

How common are they?

- Prevalence of NEAs has been estimated as 2 to 33 per 100,000 (comparable to multiple sclerosis) (Benbadis & Hauser, 2000). Therefore, in a typical town with around 300,000 people (such as Cardiff, Wigan or Doncaster) there will be about 60 to 990 people who have NEAs.

How are they diagnosed?

- Because of the physical appearance of their symptoms, people with nonepileptic attacks usually attend specialist seizure clinics. It has been suggested that up to 20% of presentations to these clinics are made up of people with nonepileptic attacks (Brown et al., 2011).
Rationale for research

- People who receive a diagnosis of non-epileptic attacks (NEAs) often describe feeling confused or angry (Carton et al., 2003) and many have difficulty understanding a psychological explanation for symptoms which are experienced as physical (Thompson 2009).

- Qualitative studies have also reported that more time and resources to understand the diagnosis are needed (Thompson et al., 2009) and that people receiving the diagnosis have an ongoing need for further information and answers to questions (Fairclough et al., 2014).

- Psychological therapy is the treatment of choice for people with a diagnosis of NEAs (Mayor et al., 2011). However, up to one third of clients who accept a referral for psychological therapy fail to attend an appointment (Howlett et al., 2007).
Service and study context

- To date, little is known about the time following receiving a diagnosis and how and whether people want to become more informed about the condition. This project aims to address this research gap by capturing patients' perspectives on information needs and their experiences of one particular psychoeducational resource.

- The website www.nonepilepticattacks.info has been developed by healthcare professionals with a specialist interest in the condition from a single neurology service. The aim of the website is to provide psycho-educational information about non-epileptic attacks to people with the condition. This includes information about the causes of nonepileptic attacks and Cognitive Behavioural Therapy (CBT) based self-help materials specific to the condition which patients can approach at their own pace.
The website

Non-Epileptic Attacks
Information about non-epileptic attacks and non-epileptic attack disorder

Why do non-epileptic attacks start?

The reasons why NEAs start are sometimes called "precipitating factors". The reasons for attacks starting can be different for different people.

Many patients report that attacks start "out of the blue" without any significant cause. However, the following list contains examples of things, which can set off NEA:

- **Negative Life Events**: NEAD can develop after a range of bad experiences. Nine out of ten people with NEAD have had traumatic life events in the 12 months before their attacks started. These events include experiences like injuries, accidents, being a victim of a crime, rape, meeting a previous abuser, surgical procedures, giving birth and undergoing anesthetics, death of or separation from family members or friends, job loss, earthquakes, relationship difficulties and legal action.

- **Stress and dilemmas**: NEAD may also develop when people face difficult choices. People sometimes talk of "unspeakable dilemmas" because the hard choices, which can contribute to NEAD, may be difficult to discuss with others. For instance, someone may feel duty-bound to look after a sick and elderly parent although they cannot cope with the many challenges involved in providing this care. Some choices may be so
Present study

- Gaining service users’ perspectives is central to developing ‘needs-led’ and patient-centred services (Mockford et al., 2012).

- This study aims to explore the ways in which people who receive a diagnosis of nonepileptic attacks use the online psychoeducation resource [www.nonepilepticattacks.info](http://www.nonepilepticattacks.info) as a means of gaining further information about the condition.

- Using qualitative methodology, it will consider the potential barriers and facilitators to engaging with the website and explore the perceived benefit of the website in understanding and adjusting to the condition.
Method

Participants

- Up to 10 people who have recently received a diagnosis of NEAs from one single Neurology service will be recruited to the study.

Recruitment

- Participants identified by neurologists and asked whether they are interested in being contacted by the researcher to hear more about a study.
- Semi-structured interviews carried out either over the telephone or face to face.

Analysis

- Interview transcripts analysed using Thematic Analysis (Braun & Clarke, 2006).
Progress so far

Project
- Ethical approval (partial review) and R&D approval received December 2015.
- One interview completed and two arranged (tomorrow)
- Possibility of using existing data (6 transcripts)

Write-up
- Introduction and Methods
- References and Appendices

Still to do...
- Interviews
- Transcriptions
- Analysis
- Write-up Results and Discussion
Reflections and top tips!

- Start early... seriously!
- Agree contracts with supervisors
- Partial ethical review if possible
- Pester, pester, pester
- Plan B - give yourself options
- Try to speak with participants where possible
- Learn to multi-task (do what you can, when you can)!
References


Thank you for listening.

Do you have any questions?