The experience of seizures: epilepsy and non-epileptic attack disorder

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Section 1: Literature Review

• A meta-synthesis of the experience of living with epilepsy
• Including articles from western and non-western countries, focusing on an aspect of an adult’s first hand experience of living with epilepsy
• Range of qualitative methodologies as long as they were able to be classified within the typology of qualitative findings by Sandelowski and Barroso
Articles

• Fifteen studies met the inclusion/exclusion criteria- sixteen papers
• Four studies in Sweden, three in the UK, three in the USA, one in each of Malaysia, Cameroon, Australia and Iran.
• 522 participants across the studies, age range 18-69
Findings

• Making sense of epilepsy: “it affects your perception of yourself”
Identity

• Participants described how epilepsy challenged their identity, making them feel different to others, seeing themselves as ‘disabled’, reducing confidence and changing their role (i.e. parents feeling like children)

• Impact of unpredictability of seizures challenged the stability of identity
Appraising epilepsy

• Epilepsy was seen as resulting in a loss of power and control
• Some descriptions of epilepsy as a curse or punishment
• Some found a way to accept/live with it—seeing it as “God’s will”
• Some descriptions of growth as a result of epilepsy
• The cost of epilepsy: “getting epilepsy has put me in poverty”
Relationships

• A significant area of loss for participants
• Descriptions of loneliness and a life of seclusion
• Expectations of being excluded from society
Employment

• Employment difficulties evident across narratives
• Problems finding and maintaining employment
• Both in terms of reaction/acceptance of others, and of ability to maintain employment
• Huge implications in some countries (i.e. where social security was limited)
Meaningful activities

- Participants described activities that were previously helpful in maintaining quality of life being lost due to epilepsy
- Life became less enjoyable for some
- Loss of driving had major implications
- Loss of normality
• Significance of others in coping with epilepsy: “my family have always helped me”
• Descriptions of ways in which participants were supported by others and the importance of this in consequently being able to cope

• Descriptions of how having the support of family was helpful in maintaining a sense of worth

• At times family could be over-supportive and participants found this suffocating

• Some participants also described significance of spirituality in coping with epilepsy
Section 2: Research paper

- How do individuals understand a diagnosis of non-epileptic attack disorder?
Study characteristics

• Qualitative study using IPA
• Semi-structured interviews with 6 participants
• 3 male and 3 female participants
• Working age adults
• On a waiting list for neuropsychology input but not currently in therapy
• Self-identified as struggling to make sense of their diagnosis of NEAD
• Did not also have epilepsy
NEAD is a confusing diagnosis: “all it means is its not epilepsy”

- NEAD was described by all participants as poorly understood - by themselves, the public and professionals
- Discussions of labels used to describe NEAD - pseudo, non-EPILEPTIC
- Misdiagnosis of epilepsy common
- Discussions around controllability
- Move from physical to psychological was frightening for some
• Some descriptions of the diagnosis being reassuring- that it wasn’t something more serious (i.e. brain tumour)
• “curability” was important for some
Legitimising the illness: feeling “like a bit of a fraud”

• Social comparisons of the symptoms and cause of NEAD
• Left some participants feeling invalidated
• Some felt that without finding the cause’, NEAD was not something legitimate for them
• Descriptions of whether or not NEAD was a legitimate medical condition
• Some descriptions of NEAD being an illness just like any other, and that the treatment (therapy) was just a different kind of medicine
NEAD as impairing life and impacting on identity: “I want to be more me again”

- Changes to sense of self as a result of NEAD
- Change in roles in relationships - i.e. a participant feeling that he was no longer able to be the ‘man’ in his relationships as he was not able to drive his wife around anymore
- Loss of driving important in terms of roles for parents too
- Loss of independence - NEAD left some participants feeling vulnerable and not able to be alone
• Loss in relationships, employment and social support
• NEAD left some participants feeling difficult to be around
• Descriptions of feelings of hopelessness
Clinical implications

• Importance of individualised care for individuals with NEAD

• Some participants wanted to find the cause of their condition while others found this prospect frightening

• One size does not fit all

• Implications regarding increased control of seizures increasing sense of self-blame

• Importance of psychoeducation regarding NEAD
Limitations

• Waiting list for psychological therapy therefore possibly more open to psychological explanation
• Participants recruited from the same service
• Questions over six as a sample size- although is commensurate with recommendations of IPA (Smith, Flowers & Larkin, 2009).
Future research

• Those who do not feel the diagnosis is one they can accept- maybe direct from neurology clinics (i.e. those who will not agree to psychology referral)

• Explore the various treatment interventions- understand specifically what individuals want from treatment

• Clinical psychologist’s point of view- what it is like to work with individuals with NEAD, especially in the client continues to struggle to make sense of it

• Research into identifying an acceptable and useful name for NEAD