



# Exploring the role of knowledge of condition and psycho-social profiles of young people with epilepsy during transition☆



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## ABSTRACT

Transitioning from paediatric to adult care can be a particularly challenging time for young people with epilepsy and research has shown that there are a range of factors which may influence a young person's ability to successfully cope with this difficult time. The following study aimed to explore the psychosocial characteristics of this transitioning population, as well as investigate how knowledgeable the young person and their parent/carer are of their own condition throughout transition. Young people with epilepsy were recruited from two specialist epilepsy clinics in the North West and allocated to one of three groups; Group 1 pre-transition, Group 2 transitioning, and Group 3 post-transition.

Results found that the young person's knowledge increased significantly throughout transition, whilst parent/carer's knowledge decreased. In addition, anxiety was found to be significantly lower in Group 2 (transitioning group) compared to Group 1 (pre-transition) and Group 3 (post-transition) and a number of significant gender differences were also identified across the groups. The study highlights the importance of considering all relevant psychosocial factors, such as anxiety, gender and the degree of knowledge the individual holds of their own condition during the transition process in order to develop psycho-educational programmes and transition pathways.

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## 1. Introduction

Adolescence is regarded as a challenging time, with many physical and psychological changes and social pressures. It is often a period of increased stress and anxiety, that occurs during a time of multiple changes in a young person's (YP) life [1]. The teenage years are central to forming the foundations for life-long health behaviours and are recognised to be a crucial time for the acquisition of knowledge and the move towards achieving independence [2,3].

This challenging time is of particular concern for YP with complex chronic health conditions, such as epilepsy. Epilepsy is recognised to be the most common neurological disorder in YP, affecting around one in 240 children in the United Kingdom (Joint Epilepsy Council, 2011). It has been reported that young people with epilepsy (YPWE) show significantly higher levels of depression, anhedonia, social anxiety and obsessive traits compared to YPs without epilepsy [4]. Recent studies have demonstrated that in addition to the increased likelihood of psychological problems, this particular period may be difficult to navigate due to many factors including the unpredictability of seizures, lack of control

over one's condition and the experience of stigma and social withdrawal [4–6]. Research studies have documented that psychosocial difficulties can persist into adulthood and that adults with epilepsy are more likely to experience episodes of depression and anxiety, difficulties with peer relationships, poor self confidence and self-esteem, and social mal-adjustment compared to the general population [7–9].

When approaching adulthood, YP are expected to transfer from paediatric into adult healthcare services. It is noted that many factors, both external such as the service provision and internal factors such as mood, resilience and attitude of the YP are involved in a successful transition. These will now be discussed further.

When process is completed well, YP are more likely to engage with their healthcare providers and adhere to treatment and it is thought that this is a factor that can enhance their quality of life and lead to better long term outcomes [10]. Recent research has described the transition journey as difficult and problematic for YPs [11–14]. Expectations are often very different in adult services compared to paediatrics. In addition to the normal pressures of entering adulthood a YPWE is expected to take on responsibility for the management of their own condition; including adherence with antiepileptic medications, managing seizure activity, engaging in healthy lifestyle behaviours and actively participating in decision making with healthcare providers [5,6,15–17].

Barriers to successful transition in epilepsy have been extensively documented [4,18]. Challenges can arise when the YPWE fails to engage

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with their treatment or adult care provider, or displays risk taking behaviours. Research has found this to be more prevalent in YPWE compared to other chronic health conditions such as Asthma or Diabetes [19–21]. Research has shown that YP who display a negative attitude towards their condition, are more likely to have behavioural problems and struggle both vocationally and academically [22–24]. Furthermore, it has been shown that this negativity can be fostered by a lack of knowledge about their condition and a desire to control and exert their independence [5].

A growing body of research has found there to be a direct link between knowledge of condition and psychosocial outcomes in YPs with chronic illnesses [25,26]. YP who lacked knowledge of their condition have displayed higher levels of depression, social anxiety and lower levels of self-esteem [27–29]. Therefore this suggests that being informed about one's own condition can promote better treatment adherence; independence; improve patient wellbeing; satisfaction; and overall quality of life [30].

In addition to knowledge, research has shown there to be other moderating factors that are associated with quality of life during transition. Factors such as confidence and self-efficacy, autonomy, resiliency and mastery have all been identified as protective factors during transition [29,31,32]. These moderating factors can be used to tailor interventions for YPWE during the transition process.

This study set out to assess how knowledge of own condition (as opposed to epilepsy in general) is associated with depression, self-esteem, and social anxiety. Resilience (the ability to weather adversity or to bounce back from a negative experience) will also be measured to explore any possible association between resiliency factors such as mastery (ability to interact with and enjoy cause and effect relationships in the environment – underpinned by optimism, self-efficacy and adaptability) and relatedness (feeling securely related to individuals in a social environment) with knowledge and psychosocial outcomes.

## 2. Materials and methods

### 2.1. Study participants

A total of 60 YPWE and 60 parents/carers were recruited to the study. Participants were identified and recruited using an availability sampling strategy from two specialist epilepsy centres in the North West of England. The paediatric and adult centres are separate and the transition involves a transition of the YP's care to a new medical team at a new hospital site. As such, participants were recruited from both centres. At present there is not a transition pathway in place at these centres. Participants were recruited on a voluntary basis over a nine month period using posters in clinics, invite packs and word of mouth in both the Neurology and General Paediatric clinics.

Participants who met the inclusion criteria were invited to participate via post, once informed consent was obtained an appointment was arranged either in clinic or at the participants' home. Three YPWE who volunteered to participate were excluded as they were deemed to have a severe learning disability (defined as an inability to provide informed consent and/or were unable to complete the questionnaires and neuropsychological tests).

Participants were categorised into 3 groups: Group 1, pre-transition (YPWE aged 12–14), Group 2, transitioning (YPWE aged 15–18), and Group 3 transitioned (YPWE aged 19+).

### 2.2. Data collection

Demographic and clinical information collected included: age, gender, schooling, age at diagnosis, current medication, seizure type and frequency (in the past 12 months). All YPWE recruited to the study completed the following measures: neuropsychological subtests from the WASI-II, psychosocial questionnaires (measuring anxiety, depression and resilience) and a questionnaire that measured knowledge

of their own condition (epilepsy). Each parent/carer completed the knowledge questionnaire, in relation to their dependent's condition (see Section 2.3 for a description of the tests and questionnaires). The WASI-II took approximately 20–30 min to administer, the questionnaires took the YPs approximately a further 20 min to complete and the parents' questionnaire took about 5 min to complete.

All assessments were administered and scored independently by a trained researcher. Study procedures, materials and the assessments used were granted ethical approval by the NHS National Health Research Authority.

### 2.3. Measures

#### 2.3.1. Knowledge of own condition questionnaire (EKP-P)

Knowledge of epilepsy was assessed using the short version of the EKP-P [33]. The short EKP-P is a 9-item true/false questionnaire that assesses an individual's knowledge of his or her own condition (epilepsy). Participants' responses were checked, by the researcher, against medical notes and scored on a 3-point scale (0 = Incorrect/Does not know, 1 = Poor description/Poverty of content, 2 = Adequate description). Questionnaires completed by the parents/carers were also checked and scored to allow a comparison of their knowledge scores with the scores of the YP.

#### 2.3.2. Wechsler Abbreviated Scale of Intelligence (WASI-II)

The WASI-II provides a brief, reliable measure of cognitive ability [34]. Two sub-tests were administered; Block Design and Vocabulary. The Block Design subtest is made up of 13 items and designed to measure the ability to analyse and synthesise abstract visual stimuli. The Vocabulary is made up of 31 items, 3 picture items and 28 verbal items, and is designed to measure word knowledge and verbal concept formation. An age-controlled scaled score was obtained for each subtest, and summated to achieve a full scale IQ (FSIQ-II).

#### 2.3.3. The self-report Resiliency Scales for Children & Adolescents (RSCA)

The Resiliency Scales for Children and Adolescents [35] is a reliable and valid measure comprising of between 19 and 24 questions that measure 3 core attributes of resilience. Two of the scales were administered: Sense of Mastery (comprised of 20 measuring optimism, self-efficacy, and adaptability) and Sense of Relatedness Scale (comprised of 24 measuring, trust, support, comfort, and tolerance). Each item was scored on a 5-point response scale (0 = never, 1 = rarely, 2 = sometimes, 3 = often, 4 = almost always). Total scores were calculated for each individual scale (Mastery and Relatedness), and these scores were summated to achieve an overall score for resiliency.

#### 2.3.4. The Spence Children's Anxiety Scale (SCAS)

The Spence Children's Anxiety Scale is a reliable and valid measure consisting of a questionnaire that assesses anxiety in YPs [36,37]. This is a 44 item scale designed to assess six domains of anxiety: 1. generalized anxiety; 2. panic/agoraphobia; 3. social phobia; 4. separation anxiety; 5. obsessive compulsive disorder; and 6. physical injury fears. YPWE were asked to rate the degree to which they experienced each symptom on a 4-point frequency scale (0 = never, 1 = sometimes, 2 = often, 3 = always). An overall score was calculated by summing all items.

#### 2.3.5. Beck Youth Inventories — Second Edition (BYI-II)

The Beck Youth Inventory comprises of 5 reliable and valid independent self-report questionnaires that assess symptoms of depression, anxiety, anger, disruptive behaviour, and self-concept in YPs. Each questionnaire contains 20 questions about thoughts, feelings, and behaviours associated with emotional and social difficulties in YPs [38]. Two of the questionnaires were administered; the Beck Self Concept (BSCI-Y) and the Beck Depression Inventory (BDI-Y). The BDI-Y assesses symptoms of depression, such as negative thoughts, feelings of

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