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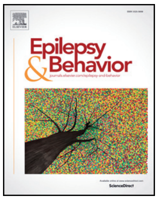

The Temple Star Transitional Model of Care for epilepsy; the outcome of a quality improvement project

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ABSTRACT

Objective: The aim and objective of this study was to assess the knowledge and views of parents on transitional and adolescent care in young adults with epilepsy, and to develop a transitional and adolescent program for epilepsy.
Methods: Data were collected from questionnaires completed by parents during focus groups exploring transitional care and inherent issues for young adults, aged 12–18 years, with epilepsy. The questionnaire assessed the current knowledge and views of parents of children with epilepsy on transitional care, and following a presentation on "Transition in Epilepsy" (including themes such as self-advocacy, independent healthcare behavior, sexual health, psychosocial support, educational and vocational planning, health and lifestyle issues) assessed feedback on the proposed model of care in transitional and adolescent care.
Results: Data were collected from 34 parents; the majority of parents, 74% (n = 25), wish their children to be transitioned and transferred over to the adult epilepsy sites at the age of 18 years. Over 82% (n = 28) of parents believe the concept of transition should be introduced between the ages of 12–16 years.
Conclusion: This quality improvement initiative identified the need for transitional care to begin at an early age. This study engaged parents in a process to improve adolescent and transitional care for adolescents with epilepsy. This study also highlights the importance of introducing a detailed preparatory phase for a transitional and adolescent care in epilepsy.

1. Introduction

Epilepsy is one of the most common neurological disorders and can affect anyone, at any age [1,2]. In 2009, a prevalence study of epilepsy in Ireland identified that approximately thirty-five thousand people aged five years and older were being treated for epilepsy [3]. However, this study was unable to identify accurately the number of adolescents with epilepsy in Ireland. Adolescence is an extremely important period of physical and psychological development, and it is in this period that good health habits can have a significant impact on future health practices [4]. Adolescence is also the first time that patients may be exposed to high-risk behavior [5]. In the context of an adolescent with epilepsy, alcohol consumption, unplanned pregnancies, and medication noncompliance may have more serious implications than in adolescents without medical issues [6,7].

Adolescent medicine can occupy an uneasy position between pediatric and adult care, often failing to address the specific care needs of the young adult and their family [8]. Bustreo [5] states that "*Adolescents have been entirely absent from national health plans for decades*". Transitional care aims to prepare and coordinate transfer of young adults with a chronic disease from a pediatric setting to an adult health service [9].

Carrizosa et al. [10] conducted a review of five international transitional care models in epilepsy including: France, Canada, Germany, Colombia, and the United Kingdom. These models varied between the different countries; the review identified a mixture of combined Pediatric and Adult Neurology clinics. Some of these clinics are nurse-led and/or physician only clinics. This review did not favor one particular model of care, rather it highlighted that there was "no prefect model" that included all the core concepts of transitional care. The review also highlighted the lack of data on the evaluation of the effectiveness of these transitional care models [10].

Some of the recommendations of this extensive review included the implementation of a multidisciplinary approach, in particular for the young adult with an intellectual disability and multiple comorbidities.

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The report also recommended that group sessions may be beneficial to discuss psychosocial issues and challenges facing the adolescent with a diagnosis of epilepsy [4].

Temple Street Children's University Hospital (TSCUH) is Ireland's second largest pediatric hospital, with a large catchment area for secondary, tertiary and quaternary epilepsy referrals nationally. The aim of this study is to assess the views of parents on when they would like transitional care to begin and in what capacity, and to design a transition program to meet those needs.

2. Methods/intervention

Focus groups were set up for parents who had a child at mainstream school with epilepsy aged between 12 and 18 years attending this service. Following a presentation on “Transition in Epilepsy” (including themes such as self-advocacy, independent healthcare behavior, sexual health, psychosocial support, educational and vocational planning, health and lifestyle issues), feedback was obtained from parents on the proposed model in transitional and adolescent care [see supplemental data]. The questionnaire assessed the knowledge and views of parents of children with epilepsy, on transitional care. Based on the results of the parental engagement groups, an epilepsy transition program for adolescents attending TSCUH was designed.

2.1. Inclusion and exclusion criteria

The parents and guardians of patients with epilepsy from the ages of 12–18 years attending the neurology services were included in this study. Both mothers and fathers were invited to participate in these focus groups. Parents of children with moderate to severe disabilities with multiple comorbidities were excluded, as they require input from other subspecialties to manage their comorbidities. The purpose of this study was solely to assess the knowledge of transitional and adolescent care in epilepsy.

2.2. Research design

The research design was employed by using a mixed method approach, comprising two methods, both quantitative and qualitative [11]. The quantitative data were collected by questionnaires, the participants' answers were coded, entered, and then analyzed by an excel spread sheet. The qualitative data were analyzed by a research assistant; the transcribed comments were summarized, and divided into common core concepts of transitional and adolescent care. There was a total of 5 focus groups, with 34 participants, both mothers and fathers. Each focus group lasted for approximately 2 h, with each participant only required to attend a single focus group. There was an average of 6.5 parents participating in each focus group, and which was mediated by a Registered Advanced Nurse Practitioner (RANP) in Children's Epilepsy.

2.3. Data collection and analysis

The questionnaire assessed the knowledge and views of parents of children with epilepsy, on transitional care. A research assistant was charged with the task of transcribing comments, independent from the department or epilepsy service, thus reducing the risk of bias. The questionnaire consisted of open and closed questions, which were completed voluntarily and anonymously by parents and guardians over the age of 18 years. This study was reviewed by the Ethics and Research Committee at Temple Street Children's University Hospital, and there were no concerns identified by the committee.

3. Results

Table 1
Parent's views on transitioning process.

Questions	Response
Do you know what transitional care is?	Yes 62% (n = 21)
Should teenagers have 1–1 sessions without their parents present?	Yes 68% (n = 29)
Should there be focus group for teenagers?	Yes 97% (n = 33)
At what age, do you think a young adult should be transitioned to adult services?	74% (n = 27) opted for 18 years
Should there be separate adolescent and transitioning clinics?	Yes 94% (n = 32)

Data were collected from 34 parents over the course of four focus group sessions (Table 1). The majority of parents (74%, n = 25) wish their children to be transitioned to the adult epilepsy sites at the age of 18 years. Overwhelmingly, parents (82%, n = 28) believe the concept of transition should be introduced between the ages of 12–16 years, and indeed almost all (90%, n = 31), wanted self-advocacy themes to be introduced to children between 12 and 14 years. In addition, the majority of parents (88%, n = 30) also wanted independent healthcare behavior, educational and vocational planning, and sexual health topics to be introduced between the ages of 12 and 16 years (Table 2). Likewise, 97% of parents would like a peer-support group for their children, and the majority also desired parallel sessions for themselves to discuss issues surrounding being the parent of an adolescent with epilepsy.

A number of themes were raised by parents at the focus groups and discussed in more detail. Parents were keen that certain lifestyle issues which confront all adolescents but may have more serious implications for people with epilepsy, including under-age alcohol consumption or substance abuse, sleep hygiene, and the management of stress be addressed with the children.

One major theme reported by parents concerned the unwillingness of adolescents to disclose diagnosis of epilepsy to peers. Adolescents were afraid of being labelled or excluded from sports and other activities by school peers, and parents were unanimous in agreement that adolescents would benefit from meeting other teenagers with epilepsy.

Parents were concerned that they had consented to antiepileptic medications that may have implications for reproduction later on and would like more detailed discussions regarding selection of specific antiepileptic drugs and potential side effects at an early stage both with the adolescent and parent. They were also keen that adolescents be encouraged to take responsibility for taking medications.

4. Outcome/intervention

Based on the results of the parental focus groups, we prioritized the preparatory phase of transitional care and developed the following program which is currently operating at TSCUH.

4.1. The Temple Star Transitional Model of Care

The Temple Star Transitional Model of Care was developed. This included the development and implementation of a three-tier model of care:

Table 2
Core concepts of transitional and adolescent care.

Core concepts	Number of parents in agreement	Age group at which parents feel it should be discussed
Self-advocacy	90% (n = 31)	12–16 years
Independent health behavior	88% (n = 30)	12–16 years
Sexual health	88% (n = 30)	12–16 years
Lifestyle	94% (n = 32)	12–16 years
Vocational and education training	97% (n = 33)	12–16 years