



A UK survey of the experience of service provision for children and young people with epilepsy



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ABSTRACT

Purpose: To survey patient and carer experience for children and young people with epilepsy across the United Kingdom.

Methods: We used a Patient Reported Experience Measure methodology to explore perceived satisfaction with their epilepsy service. A survey collected anonymised proxy data on demography and illness severity, and perceptions of interaction with clinicians, ease of access to the service and the quality and quantity of epilepsy information provided. The questionnaire was completed by the child's or young person's carer or by the young person.

Results: Survey questionnaires were distributed across all of the 192 paediatric units providing epilepsy care for children in the UK. 145 units (75%) submitted data and there were 2335 responses. 90% of young people and 86% of carers were satisfied with the care they had received. Using multi-level logistic regression modelling, those factors most strongly affecting satisfaction were determined. While many proxies of illness severity adversely affected satisfaction, comorbidity did not. A dedicated clinic setting, perceived adequate information and guidance on restrictions on their child, if any, all improved satisfaction. However, the significantly strongest factor influencing satisfaction was “ease of access” to the service.

Conclusions: These data demonstrate the feasibility of collecting large population sizes to allow a better understanding of the needs of children and young people accessing an epilepsy service. They allow the identification of factors most closely linked to patient satisfaction and provide potentially valuable information on how to improve the quality of care of children and young people with epilepsy.

1. Introduction

There has been increasing acknowledgement of the need to include patients' experiences in evaluation of healthcare and that monitoring healthcare effectiveness from the patient perspective can be as important as using clinical outcome measures to enable quality improvement [1]. The World Health Organisation emphasises the importance of understanding patient satisfaction and responsiveness to care experiences. Patient satisfaction with aspects of non-medical care is associated with better engagement with treatment, appropriate care-seeking and understanding and retention of medical information [2].

Historically, most attempts to capture patient perspectives relied on questionnaire measures with patient satisfaction measures adopted as a proxy for healthcare quality. Such methods have come under criticism for their more subjective nature and that general satisfaction may be unduly influenced by variables unrelated to patient care including

“gratitude bias”, health status and prior expectations such as a desire for a particular medication or treatment [3–5]. There have been attempts to move away from more general satisfaction measures with the development of patient reported measures which fall into two broad categories; Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs). PROMs are standardised, validated instruments that are used to measure patient perceptions of factors such as symptoms (degree of impairment), functioning (disability), health status and quality of life [6]. PREMs, in contrast, aim to capture patients' experience of healthcare by focusing on more specific aspects of the core process such as whether they are seen on time, the information provided, interactions with staff and clinicians [7]. In obtaining feedback on services and care provision and identifying areas for potential improvement, PREMs are accepted as more valid and reliable tools than generic satisfaction measures.

With the growing recognition of the need for patient and family

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involvement, government health policy, in both the UK and internationally, has emphasised the need to involve children and young people more in the shaping of services [8]. PREMs are acknowledged as a useful tool in facilitating children and young people and their families to make contributions in evaluating patient care and recommendations for improvement.

A national survey (“Epilepsy12”) of the care of children and young people with epilepsy in the United Kingdom was published in 2014 [9]. The overall aim of the audit was twofold: To facilitate health providers and commissioners to measure and improve quality of care for children and young people with seizures and epilepsies; and to contribute to the continuing improvement of outcomes for those children, young people and their families. The main survey consisted of 3 domains. Firstly, a series of “Service Descriptors” describing the available clinical personnel and equipment resource in each unit at a point in time. Secondly, 12 quality measures (“Performance Indicators”) explicitly linked to current guideline recommendations from NICE and SIGN [10,11]. Thirdly, a “Patient Reported Experience Questionnaire”. This paper describes only the third component of the survey; the aim of this study was to collate information about the experience of clinical care of a young person with epilepsy and their carers. We wished to analyse which factors were most likely to influence perceived satisfaction with the epilepsy service and to include variables such as service provision, proxy indicators of illness severity and factors such as accessibility to the service and information provided.

2. Methods

2.1. Epilepsy12 audit

As part of this audit, a questionnaire was devised to capture the experience of users of the paediatric service over a defined 12 month period. The questionnaire consisted of two sections, the first to be completed by the parent or carer, and the second by the young person or, if that was not possible, by the parent or carer. The first section collected information about the young person with epilepsy: gender, age, frequency of seizures, associated comorbid conditions (such as cerebral palsy, intellectual disability, attention deficit hyperactivity disorder and autism), age at onset of epilepsy, prescribed anti-epileptic medications, type of NHS services used, ease of contacting the service, and experience with the care received (namely, whether participants were satisfied or unsatisfied with the care received over the past 12 months). The second section included a number of statements about the perceived interaction with healthcare staff in the clinic, ease of being able to contact staff outwith a clinic appointment, and the perception of the quantity and quality of information given about their condition. These attitude statements were assessed on a 5-point Likert scale. This section also asked whether more information was desired on a number of aspects of epilepsy care. The final section asked the respondent to list the three best things and the three worst things about the epilepsy service as free text responses. These data have not been reported within this study as we intend to publish those findings separately.

The questionnaires were anonymised except for which UK audit unit the completed questionnaires originated from. This allowed the analysis to be adjusted with some of the audit level “service descriptors” which may influence a user’s perception of the service. We had information on three audit unit level descriptors: whether or not the audit unit hosted paediatric neurology clinics, the number of full time equivalent (FTE) epilepsy specialist nurses employed by the audit unit, and the FTE paediatric consultants with epilepsy expertise employed by the audit unit.

The UK has 197 distinct audit units defined; 192 agreed to participate in the PREM domain. Each participating unit was asked to distribute at least 25 patient questionnaires across a range of different clinic provisions in their audit unit area, over a fixed 3 months period. The questionnaires were completed and returned anonymously to clinic

staff. Collation and data entry were undertaken by the research division of the UK Royal College of Paediatrics and Child Health.

2.2. Data analysis

The data were transferred to a SafeHaven at the University of Dundee for analysis and interpretation and analysed using SPSS version 22. Overall proportions of the responses were calculated and, where performed, bivariate differences between those satisfied and not satisfied with their care were assessed using the chi-square. Three multi-level regression models (Generalized Estimating Equations) were constructed to assess the influence of different factors on satisfaction; first the influence of demographic, illness severity variables and service related factors; second, the influence of attitude statements; and third the types of additional information wanted about epilepsy. Each regression model included the 3 audit level descriptors, and the person who completed the questionnaire.

3. Results

Questionnaires were received from 145 of the 192 audit units who agreed to participate and 2335 completed questionnaires were returned. The majority of the questionnaires (68%) were completed by the parent or carer of the young person with epilepsy. From the bivariate analysis, a higher proportion of young people who answered the questionnaire was satisfied with the epilepsy care they received compared to the parent/carers (90% versus 86%) (Table 1). Neither the gender of the child/young person nor the presence/absence of comorbidities was related to the satisfaction level reported by the parents/carers (Table 1). The majority of the respondents were aged between 5–15 years at the time of the survey and, although the majority of respondents were satisfied with the epilepsy care that they received, more parents/carers whose children were under 5 years at the time of the survey were dissatisfied with or unsure about the epilepsy care received. The majority of respondents were first assessed for their epilepsy more than two years before the survey date, but those respondents whose child/young person was first assessed less than one year before the survey were slightly less satisfied or unsure about the care received. The responses were relatively well distributed by duration of epilepsy, with the groups with the shortest durations less satisfied with their care or unsure of how they felt. The parents/carers whose child had a duration of epilepsy of between 5.0–6.9 years had the highest percentage who were unhappy with the care received. Just over one-quarter of the sample experienced a low frequency of seizures (less than one per month), 15% experienced daily seizures and 15% experienced only blank spells. Children/young people experiencing frequent seizures (one or more per week, but not daily) were less satisfied with their epilepsy care than others with different seizure frequencies. The majority of the children/young people were taking one epilepsy drug at the time of the survey, although 11% were taking no specific epilepsy drug. More respondents whose child was not taking drugs were unsure about whether they were happy with their child received and more respondents whose child was taking two or more drugs were dissatisfied with the care that their child received (Table 1).

The parents/carers were asked about the type of NHS services that they had experienced over the 12 months prior to the survey. Services were grouped into three categories (attendance at an emergency or primary care facility; attendance at a general paediatric clinic; attendance at an children’s epilepsy clinic). Only one category (attendance at an emergency or primary care facility) influenced satisfaction levels. Just over one-third of the children/young people had been treated in this category and parents/carers of these children/young people were more dissatisfied with the care received (Table 2). The majority of children/young people had access to NHS services with epilepsy specialist nurses (77.2%) and paediatricians with expertise in epilepsy (95.2%), and 89% had access to a paediatric neurology clinic.

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