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# Epilepsy services in Ireland: ‘A survey of people with epilepsy in relation to satisfaction, preferences and information provision’

Louise Bennett<sup>a,\*</sup>, Michael Bergin<sup>b</sup>, Martina Gooney<sup>b</sup>,  
Colin P. Doherty<sup>c</sup>, Cara Synnott<sup>c</sup>, John S.G. Wells<sup>d</sup>

<sup>a</sup> Department of Nursing, School of Health Sciences, Cork Road, Waterford Institute of Technology, Waterford, Ireland

<sup>b</sup> Department of Nursing, School of Health Sciences, Cork Road, Waterford Institute of Technology, Ireland

<sup>c</sup> St. James's Hospital, Dublin, Ireland

<sup>d</sup> School of Health Sciences, Waterford Institute of Technology, Cork Road, Waterford, Ireland

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## KEYWORDS

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## Summary

**Background:** A challenge facing modern health care systems is to develop and implement new models of service that deliver increased capacity while providing a higher-quality, more cost-effective service within resource constraints. Incorporating the experience of people with epilepsy must be seen as central to the effectiveness of service design and delivery. This paper, therefore, reports the views of people with epilepsy with regards to health service delivery in Ireland.

**Method:** A cross-sectional descriptive survey design involving both quantitative and qualitative items was administered to a convenience sample of one hundred and two people with epilepsy ( $n = 102$ ) attending an epilepsy specialist centre.

**Results:** Despite high levels of satisfaction with hospital and primary care, participants offered several suggestions to improve healthcare delivery, such as: less delay in accessing specialist care and hospital appointments; better communication; and easier access to investigatory services. Findings demonstrate that for people with epilepsy the burden of the disorder is substantial and complex encompassing social, psychological and structural difficulties. Poor information provision particularly among women is reported. Furthermore, a lack of empowerment in people with epilepsy is highlighted.

\* Corresponding author. Tel.: +353 051 845558.

E-mail addresses: [lbennett@wit.ie](mailto:lbennett@wit.ie) (L. Bennett), [mbergin@wit.ie](mailto:mbergin@wit.ie) (M. Bergin), [mgooney@wit.ie](mailto:mgooney@wit.ie) (M. Gooney), [cpdoherty@stjames.ie](mailto:cpdoherty@stjames.ie) (C.P. Doherty), [cara-synnott@hotmail.com](mailto:cara-synnott@hotmail.com) (C. Synnott), [jswells@wit.ie](mailto:jswells@wit.ie) (J.S.G. Wells).

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*Conclusion:* This study has implications for the reform and development of epilepsy services in relation to practice, education and research. It provides a basis for an evaluation of current practice and identifies opportunities for future service reorganization to improve the quality and efficiency of healthcare provision.

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## Introduction

Irish healthcare policy emphasizes the need for more collaborative approaches in the management and delivery of care (DOHC, 2008). Indeed, people's experiences are now central to assessing performance of healthcare services as they relate to quality of care, patient engagement and enhanced accountability of clinical services to local communities (Luxford, 2012). The person with a chronic condition such as epilepsy is likely to have a life-long engagement with clinical services (Tinetti et al., 2012; Ralston et al., 2004) and therefore identifying and incorporating their experiences must be seen as central to effective service design and delivery.

This paper reports on the views of people in Ireland with epilepsy on their views of their service needs in relation to design and delivery. To date there is a lack of research internationally that explores the views of people with epilepsy with regards to these issues and in particular people with epilepsy's satisfaction with care they receive. In this context, this study provides a useful insight into these issues that may be of relevance to service development outside of Ireland.

## Background

Epilepsy is a chronic neurological disorder characterized by recurrent unprovoked seizures. It is the most common serious neurological condition after stroke (Hadjikoutis and Smith, 2005). For people with epilepsy the burden of the disorder is substantial and complex with physiological, psychological and social difficulties that limit lifestyle, education, driving and employment even where good control of epilepsy is reported (Fisher et al., 2000). Consequently, health-related quality of life is significantly poorer accompanied by higher rates of comorbidity in people with epilepsy when compared to the general population (Elliott et al., 2009). The Irish Epilepsy Association (2010) suggests that approximately half of all deaths related to epilepsy could be prevented if there was better care, education and services in place. However, a Cochrane review reports that an optimum system of care for people with epilepsy has not yet been empirically determined (Bradley and Lindsay, 2008).

In this context, a challenge facing modern health care systems is to develop and implement new models of service that delivers a high-quality, more cost-effective service that significantly improves the lives of people with epilepsy (Westbrook et al., 2009). This is reflected in recent Irish health care policy, which challenges traditional models of service delivery and cost structures with a move towards models of care that require service reconfiguration, reform and greater productivity (HSE, 2011).

With this in mind, a National Epilepsy Care Programme (NECP), under the direction of the office of Clinical Strategy and Programmes of the Irish Health Service Executive (HSE), has been charged with addressing the historic deficiencies in epilepsy care through a comprehensive change programme that delivers care from 'cradle to grave' (HSE, 2010). This programme has a 10-year vision for the transformation of epilepsy care in Ireland. It aims 'to provide the best value care for all people with epilepsy in the right place, at the right time, sharing the best available information' (ibid p. 5). This will be achieved primarily through care provision within the primary care setting involving General Practitioners (GPs) and Advanced Nurse Practitioners (ANPs) who have a specialist interest in epilepsy. These primary care professionals will collaborate with six regional epilepsy centres throughout Ireland that will be staffed by a new cohort of epilepsy nurses and supported by epilepsy medical fellowships. These services will be delivered through specified care pathways and will cover epilepsy presentations in emergency departments and medical assessment units. The NECP will also address the care of highly complex epilepsy cases.

## Current configuration of services in Ireland

Currently epilepsy care in Ireland is shared between primary (General Practitioner – GP), secondary (hospital) and tertiary (specialist epilepsy services within a hospital) services. The GP is the first point of contact for people with epilepsy and responsible for their ongoing management of care (Varley et al., 2009).

Two of the main epilepsy specialist centres for people with epilepsy in Ireland are located at St. James's (SJH) and Beaumont Hospitals in Dublin. These centres are staffed by consultant neurologists, neurology registrars, Epilepsy Specialist Nurse's (ESN) and are either reviewed by an ESN in lieu of a medical doctor or by both. However, complex cases are initially reviewed by a consultant neurologist. Information regarding the person's epilepsy and care provision is provided by all healthcare professionals within the service.

## Method

### Aim of this study

Bearing in mind the current policy emphasis and service configuration this study aims to identify the views of people with epilepsy with regards to health service delivery in Ireland. Specific objectives were set as follows:

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