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‘If only I had known’: How to reduce the risks of living with Epilepsy

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Epilepsy can be a risky business but the risks can be reduced if patient and professional work together to agree a treatment plan for their epilepsy. Patient centered care is not a new concept, but is difficult to adopt in a busy clinical setting and so patient's attitudes and concerns are rarely discussed during a consultation. As a result, we know that up to 50% of prescribed epilepsy medicine is not taken as prescribed and that risky decisions are taken by people with epilepsy that leads to poor seizure control and even sudden death. Firstly, to summarize the findings of the National Institute for Health and Clinical Excellence (NICE) Clinical Guidance on Shared Decision Making and Medicines Adherence; then to describe the work done in family practice in the UK about identifying people with epilepsy at risk of non-adherent behavior, including key questions and use of a medicines possession calculation; and finally to summarize the qualitative data drawn from families who reported epilepsy related death to the Epilepsy Deaths Register. The presentation will conclude by offering recommendations for practice to foster enhanced self-management of epilepsy.

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

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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.

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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