

## **Becoming Comfortable with MY Epilepsy: The How2tell Study**

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### **Introduction**

This short paper on Becoming comfortable with MY epilepsy is part of the How2tell study on disclosure and epilepsy. The purpose of the study is to explain how people with epilepsy (PWE) disclose information about their condition and, using this knowledge, develop a multi-media educational resource that will support PWE learn how to tell other people about their epilepsy. The inductive approach of grounded theory (Glaser, 1998) allow for a viable means to generate a robust explanation about disclosure—one that was grounded in the realities of PWE everyday life. From a healthcare and policy perspective (England, Liverman, Schultz, & Strawbridge, 2012), providing access to relevant and usable knowledge for people with epilepsy that meets their individual needs is important to enable them to participate effectively in self-care management. Grounded theory, therefore, was essential to the How2tell study, which was successfully awarded a research grant from the highly competitive Health Research Board and Epilepsy Ireland's research grant programme.

### **Methods**

To gather data on first-hand experiences of disclosure and epilepsy, in-depth interviews were carried out with 49 consenting adult people with epilepsy (18 years and over) in Ireland. In the early stages of concurrent data gathering and analysis, becoming comfortable began to emerge as a tentative category. Later, as data gathering, analysis and theoretical sampling progressed; the category was further developed to becoming comfortable with MY epilepsy.

### **Becoming comfortable with MY epilepsy**

*"I knew about it [epilepsy] to a degree, but not on a personal level . . . not the experience of it."*

A major concern identified by participants in the How2tell study related to feeling ready to start talking about their epilepsy with other people. At the time of being newly diagnosed with epilepsy, participants were at the beginning stage of coming to terms with the diagnosis and trying to understand how epilepsy would affect them personally in everyday life. Importantly, participants did not feel ready to talk about their epilepsy with

other people until they felt comfortable with the epilepsy diagnosis and, in particular, their type of epilepsy.

Becoming comfortable with epilepsy was a gradual process and developed over time. As part of the process, participants used four main strategies that helped them reach a point of feeling ready to talk about their epilepsy. The first strategy, becoming knowledgeable with MY epilepsy, involved sourcing information that was relevant to their particular type of epilepsy. Epilepsy is a complex neurological condition and encompasses a broad spectrum of different types of epilepsy and seizures, so that newly diagnosed PWE realize that they need to learn about the complexities of managing their epilepsy. Another strategy that participants use is becoming a member of an epilepsy support group. Although information on epilepsy was readily available from healthcare professionals, information booklets, Internet, and specialty epilepsy websites, participants find that joining a support group where they could meet other people with epilepsy and, importantly, meet people with their type of epilepsy is particularly helpful in becoming comfortable with MY epilepsy. A third strategy PWE use is to confide in a close friend or family member. The first time they tell someone about their epilepsy, they usually choose to tell someone who is close to them and whom they trust. Saying the word epilepsy out loud, getting used to talking to close friends, and dealing with their reactions help PWE to become more comfortable in talking about their epilepsy. The fourth strategy involves practicing telling, which is particularly helpful for disclosure in formal contexts such as a job interview, line-manager at work, or academic course director at a university/college.

*"I realized that... if I could accept it, it would be fine."*

### **Conclusion**

Becoming comfortable with MY epilepsy is a gradual process and PWE use these strategies to help them to accept their diagnosis and to reach a stage of feeling ready to talk about their epilepsy. The benefit of using Glaser's grounded theory approach is that becoming comfortable with MY epilepsy is grounded in the experiences of people with epilepsy. This is an important part in the design and development of the How2tell multi-media educational resource. As a self-management support for PWE, it is hoped that the new How2tell smartphone app, website, and booklet will be of benefit to PWE empowering them with practical knowledge about how to tell other people "I have epilepsy". It is also recognized that further research is needed to check if becoming comfortable with my epilepsy patterns out with other PWE in different cultural contexts and outside of Ireland.

### **References**

- England, M. J., Liverman, C. T., Schultz, A. M., & Strawbridge, L. M. (2012). Epilepsy across the spectrum: Promoting health and understanding: A summary of the Institute of Medicine report. *Epilepsy & Behavior*, 25(2), 266-276.
- Glaser, B. G. (1998). *Doing grounded theory: Issues and discussions*. Mill Valley, CA: Sociology Press.