Patient Education

Identifying Risks and Self-Management Approaches for Adherence and Sudden Unexpected Death in Epilepsy

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KEY POINTS

- Patient education in epilepsy is one part of quality epilepsy care and is an evolving and growing field of its own.
- Although there may be many barriers to providing appropriate and effective education in some settings, there are even more compelling reasons to educate patients and their families.
- Health outcomes, patient satisfaction, safety, patient/provider communication, and quality of life may all be affected by what people are taught (or not taught), what they understand, and how they use this information to make decisions and manage their health.
- Data regarding learning needs and interventions to address medication adherence and sudden unexpected death in epilepsy education can be used to guide clinicians in health care or community settings.
- Ideally, clinicians can enhance their individual educational efforts by encouraging the use of credible community and online information and resources to improve access to epilepsy information and support.

INTRODUCTION

Educating patients and families is a critical component of quality epilepsy care. Effective education takes time, which can be a barrier for clinicians providing care in some settings. Additionally, changing concepts in our understanding of epilepsy, comorbidities, risks, and response to treatment have complicated how and what to teach

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people, but also highlight the importance of patient education. This article discusses goals and priorities for patient education and how learning and self-management needs may vary across the spectrum and along an individual's journey with epilepsy. Evidence and best practices for 2 major areas, medication adherence and sudden unexpected death in epilepsy (SUDEP), are highlighted.

GOALS OF PATIENT EDUCATION AND SELF-MANAGEMENT

Providing information to people with epilepsy and families aims to increase knowledge and understanding of epilepsy and the specific topic(s) addressed (eg, medication, adherence, seizure types, safety, first aid). However, numerous studies and trends in education show that providing information and increasing knowledge by itself does not necessarily affect clinical outcomes or influence how a person is able to use the information to manage their epilepsy.

Epilepsy self-management education takes this a step further. Self-management concepts and approaches stress the active involvement of the person with epilepsy, family, or other caregiver with their health care team. The concept of epilepsy self-management has evolved from addressing the steps or processes needed for a person to control their epilepsy and effects of having epilepsy[1] to a focus on ways to "optimize seizure control, minimize the effects of having a seizure disorder, and to maximize quality of life in partnership with their health care provider".[2] These approaches strive to change a person's behavior and promote healthy behaviors rather than just increase knowledge. Teaching skills, building self-efficacy, and providing resources and support for people to apply the learned information to their management needs are critical aspects of self-management education.[3] Ideally the clinician works together with the patient to identify learning needs and priorities and how best to meet their needs.

The importance of patient-centered care and education was emphasized in the landmark publication, Crossing the Quality Chasm: A New Health System for the 21st Century, and is a critical factor in a model for organization and integration of care and services for people with epilepsy.[4] This epilepsy care model acknowledges that people receive care in many different settings and that both health care facilities and community supports are part of the patient's care team. Patient-centered care is at the heart of the model and ideally leads to informed and engaged patients/families working collaboratively with their health care team and community supports. This epilepsy care model assumes that patient education and self-management support occur across settings and are part of care leading to optimal outcomes and family adaptation.

CORE COMPONENTS FOR EPILEPSY EDUCATION

Many models or self-management programs focus primarily on core components to improve epilepsy management, such as managing seizures, treatments, safety, and lifestyle.[1,3,5–7] Yet epilepsy can have wide-reaching ramifications on the health of many, causing or being associated with comorbid conditions such as mood, sleep disorders, mobility, or bone health, to name a few. Epilepsy, particularly when seizures are not controlled or comorbid conditions are present, can affect one's social situation and ability to live independently. In these situations, epilepsy self-management should also address management of general health, comorbid conditions, psychosocial issues, and independent living factors, such as education, employment, living situations, finances, and other disability-related needs that affect a person's ability to live to their fullest.[8]