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Self-care strategies for children with epilepsy

Commentary

Implications for practice and research

- The impact of epilepsy may symbolize a life-changing event for the affected children and their parents.
- Epilepsy is managed by using both pharmacological and non-pharmacological approaches.
- Although, there is evidence to suggest the benefits of non-pharmacological treatment in epilepsy, there is limited study on self-management interventions for children with epilepsy.

Context

Historically, epilepsy is one of the world's oldest recognized conditions and it is dominated with fear and misunderstanding until the advent of the discipline of neurology¹. It is one of the most common chronic disabling neurological disorders in the world with serious physical, economic and discriminatory consequences in some parts of the world. Epilepsy is a non-contagious neurological medical condition resulting from outbursts of excessive electrical discharges in a group of brain cells. The disease is associated with a risk of mortality due to accidents, suicide, or sudden unexpected death in epilepsy (SUDEP)²⁻³. Although epilepsy and its treatment are complex, there is evidence to support the benefits of self-care management². This systematic review examines the benefits of self-management in improving epilepsy care².

Methods:

A systematic review was conducted by searching scientific database for studies in children and adolescence with epilepsy. In addition to a manual search, this pragmatic approach utilized data from Cochrane Epilepsy registers, Medline, Embase, CINAHL, Psych Info up until 27 September 2016. The authors screened over 4,000 papers and the researchers retrieved a final selection of seven articles reporting on six different interventions: RCTs (n = 5) and controlled before and after studies (n = 2). A two-stage selection of studies were done by two researchers who independently screen the papers, resolved any disagreement through discussion, and identified the studies based on the eligibility criteria for inclusion². The criteria for considering studies for this review include the types of studies, types of participants, types of interventions, and types of outcome measures. The data were extracted and assessed for risk of bias using Cochrane Effective Practice and Organisation of Care risk of bias criteria. The measure of treatment was reported as published in the primary research papers and the results were presented using a narrative summary. Meta-analysis was not appropriate due to methodological and heterogeneity in the studies².

Findings:

Self-management of epilepsy encompass various health related behaviours and activities that a person can learn and adapt to control the symptoms and enhance their

health and wellbeing. The study compared six education or counselling-based self-management interventions involving children and their parents (n = 5), teenagers and their parents (n = 1) and those including children, adolescent, and their parents (n = 1). The evidence from this systematic review revealed that all the interventions improved some of the outcomes². Although patients may benefit from some of the interventions, no intervention has a positive outcome across all the assessed outcomes.

This systematic review² based narrative synthesis looked at several outcomes pertaining to how the patient and their families cope with epilepsy. All the studies investigated interventions for improved self-management which includes education, counselling, or training. Although self-management is associated with positive outcomes, no single intervention offers a comprehensive improvement in a wide range of outcomes. Nevertheless, non-maleficence was ensured as none of the interventions resulted in harm.

Commentary:

The paradigm shift in chronic disease management from the basic disease model which centred exclusively on treatment by healthcare professionals to the recent integrated care approach involving the patients stresses the importance of self-management in epilepsy. This innovative model of service delivery is a collaborative approach between the patient and healthcare providers, therefore, a positive healthcare practitioner-patient relationship is central to developing a successful self-management skill²⁻³.

Self-management has a positive health outcome for patients with epilepsy, but the impact of each intervention was limited, therefore, the authors cannot recommend any single intervention as the best choice for children with epilepsy. A key importance of this systematic review to future practice is that the healthcare burden and financial cost of treating epilepsy may be reduced with a combination of appropriate innovative strategies such as self-management interventions¹⁻².

The study presents methodological deficiencies with all the studies, therefore, awareness of the limitations of this study is crucial for healthcare practitioners. Nevertheless, this database study provides clinical insight and suggest direction for future research. Further studies to bridge clinical gaps in this area needs to consider improved design and preferably RCT to increase generalisability, evaluate the effects for those subgroups that are most likely to benefit, and examined cost-effectiveness of service models².

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