

Guidelines and Quality Standards in the Care of Children with Epilepsy



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KEYWORDS

• Epilepsy • Children • Guidelines • Health services • Quality standards

KEY POINTS

- Clinical practice guidelines allow a synthesis of the best available research evidence into recommendations for best clinical practice.
- Many clinical practice guidelines in children's epilepsy are able to call on only a limited quantitative research base and rely on clinical opinion in formulating recommendations. There may be opportunities to incorporate more qualitative literature into clinical guidance.
- Implementation is vital to ensure that guidelines are translated into improved patient outcomes.

INTRODUCTION

Practice guidelines for clinical care have been in existence in various forms over many years. This article reviews the structures needed to ensure that clinical guidance is based on best available research evidence but also explores the limitations of some of the approaches in particular with regard to epilepsy care in children. Moving the recommendations that emerge from structured clinical guidance into improving quality of care remains a challenge in many health care systems, and the authors review the development of national quality standards, in this case with specific reference to the United Kingdom.

DRIVERS FOR GUIDELINE DEVELOPMENT IN THE UNITED KINGDOM

In the United Kingdom there had been a long-standing concern about the quality of care provided for people with epilepsy, both children and adults. The Chief Medical

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Officer for England commented that epilepsies had remained “in the shadows” for decades, that 5 earlier reports had remained largely unimplemented, and that the disease remained an “unglamorous” area of clinical practice.¹ That this situation is unlikely to have been unique to the United Kingdom has been reflected in the 1997 leading article in *The Lancet* on poorly treated epilepsy.²

As examples of this concern, the UK National Clinical Audit of Epilepsy-Related Death reviewed pre-death care and post-death investigations in children and adults over 12 months.³ Although the proportion of children that could be reviewed in detail was small, the key findings showed that 77% of children had what would be regarded as substandard care and that 59% of deaths in children were potentially or probably avoidable. Deficiencies identified included inadequate drug management, access to specialist care and investigations, and a lack of holistic management.

A report commissioned by the Royal College of Paediatrics and Child Health on the care of children with epilepsies by an individual UK paediatrician was published in 2003. It found that of almost 2000 children with a diagnosis of epilepsy, 32% had been misdiagnosed, either because they did not have epilepsy or the type of epilepsy diagnosed was incorrect. There seemed to be excessive and/or unnecessary drug treatment in almost one-third of children. This doctor’s practice is unlikely to have been unique; high rates of misdiagnosis have been reported from elsewhere. For example, of 223 children referred to a tertiary center in Denmark, 85% of which were already on antiepileptic drug treatment, the diagnosis of epilepsy was removed in approximately 40%.⁴

The Royal College of Physicians of Edinburgh convened a conference of interested professionals in Edinburgh in September 2002 leading to the publication of the Edinburgh consensus statement.⁵ It noted, for example, that there was an urgent need for national standards of clinical practice to be implemented and monitored. It called on the initial diagnosis of epilepsy to take place in the context of a properly resourced integrated clinical network and for patients to be seen within 2 weeks of referral. The diagnosis of epilepsy should be confirmed by a clinician with expertise in epilepsies, peer review of practice, and regular audit of diagnoses. Epilepsies should account for a significant part of this clinician’s clinical workload, equivalent to at least one clinic per week.

In large part the development of national guidelines from Scotland (Scottish Intercollegiate Guidelines Network [SIGN]) and from England and Wales (National Institute for Health and Care Excellence [NICE]) arose from these issues.^{6,7} It is likely that similar imperatives in other countries have been instrumental in decisions to introduce similar clinical practice guidelines in other countries.

DEFINITIONS OF GUIDELINES

It is nonetheless important to understand what clinical guidelines are and the basis on which they are constructed. Clinical guidelines are defined as “*systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances.*”⁸

However, not all guidelines are systematically developed and in reality may be consensus statements or a position statement by an organization, be they professional, governmental, or lobby. An interested reader looking for published clinical guidance on children’s epilepsy might enter the search term *guideline children epilepsy* into a typical Internet search engine. This would reveal some 34,000 results; even using the same search term in a medical scientific journal dedicated to identifying *best practice* literature would identify some 50 guidelines on diagnosis, 84 on

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