

Review

Patient-reported quality of life and biopsychosocial health outcomes in pediatric epilepsy: An update for healthcare providers

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ABSTRACT

In the 21st century, clinicians are expected to listen to, and understand their patients' views about, their conditions and the effects that these conditions have on their functioning, values, life goals, and welfare. The goals of this review are as follows: (i) to inform, update, and guide clinicians caring for children with epilepsy about developments in the content and new methods of research on patient-reported outcomes, quality of life, and functioning; and (ii) to discuss the value of using these concepts to explore the impact of diverse interventions that are implemented in daily practice. Drawing on the literature and our program of research over the past two decades, we focus on our current understanding of a variety of health concepts and recently acquired knowledge about their significance for the lives of patients and their families. We discuss the advantages of measuring patient-reported outcomes that tell us what is important to patients. We advise on what characteristics to look for when choosing a patient-reported measure, and the relevance of these considerations. In addition, we address gaps in research knowledge and the causes of confusion that have limited their use in our daily clinical practice.

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1. Introduction

In the past two decades, researchers have reported major developments in acquiring knowledge directly from children with epilepsy and their families concerning quality of life (QoL) and other patient-reported outcomes (PROs). This collective information, if used appropriately, could help children and their families achieve better QoL. However, there are still evidence gaps and questions that need further exploration. Regrettably, researchers have created obstacles and confusion by applying the same terms to different theoretical constructs, and different terms for the same constructs. This confusion has led, for example, to the development of different kinds of tools all claiming to measure the "QoL" of the child. Other barriers include the meager overall use of "patient- (particularly child-) reported outcome measures" (PROMs) in our daily practice.

As healthcare providers (in our case working in childhood epilepsy), we are now recognizing that we can do more for patients by expanding our focus beyond a traditional biomedical view of seizure control with

minimal adverse effects [1]. An integrated approach to QoL and biopsychosocial health challenges us to provide a broader approach to several dimensions of health, including spiritual issues in people's lives—issues that are important to children and their families and that are potentially amenable to targeted interventions. This transformative thinking, though not new, gained interest initially in North America and Europe and is now increasingly embraced worldwide. This change in perspective has been attributed to a number of factors, including the following: (i) the acknowledgment that epilepsy is a complex pervasive neurobehavioral condition; (ii) national and international recognition for the rights, dignity, and protection of disabled people, including those with epilepsy; (iii) support and awareness campaigns by organizations advocating for people with epilepsy; (iv) the development and evolution of conceptual frameworks for health, health outcomes, functioning, and quality of life; (v) the development of powerful statistical methods to explore interrelated concepts that include many relevant variables; and (vi) improvements in the development of health measurement tools that focus on patient-reported outcomes (PROs) [2].

2. What do we mean by the terms quality of life (QoL), biopsychosocial health, functioning, disability, and patient-reported outcomes (PROs)? An example of the importance of terminological clarity

There are many views on what may constitute QoL [3,p.133]. People commonly refer to the World Health Organization (WHO) concept of

Abbreviations: AEDs, antiepileptic drugs; HRQL, health-related quality of life; ICF, International Classification of Functioning Disability and Health; PRO, patient-reported outcomes; PROM, patient-reported outcome measure; QoL, quality of life; SEM, structural equation modeling; SES, socioeconomic status; WHO, World Health Organization.

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“the individual’s perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, and concerns” [4,p.153]. Thus, QoL refers to a summative judgment about all aspects of a person’s life [5]. Intuitively, any operational consideration of QoL needs to be congruent with the WHO’s QoL framework. *Health-related quality of life (HRQoL)*, as the name implies, refers to measures that purportedly assess only the aspects of a person’s life that are thought to be affected by a disorder. Because of the increasing recognition that it is difficult to attribute better or poorer life solely to the biopsychosocial aspects of a disease and its medical treatment, both QoL and HRQoL need to cover a broad notion that would include the patients’ self-reported impact of life domains such as expectations and adaptation to their health condition [6]. Importantly, QoL, HRQoL, and biopsychosocial health are distinct concepts.

The model of biopsychosocial health was introduced by Engel to expand the dominant but limited biomedical model by adding psychological and social factors, thereby giving a more holistic understanding of the interaction among biological, psychological, and social factors in the illness process [7]. The WHO’s biopsychosocial concept of *functioning* is an advanced development in conceptualizing health. The WHO *International Classification of Functioning, Disability and Health* or *ICF* (2001) describes health through the lens of functioning [8]. The ICF is an interdisciplinary noncategorical approach, applicable to all fields of medicine. The ICF reminds people about the integration and interactions among the elements of the biological model of health (body function and structure including mental health), and those of the social model of health (activities, which, incorporate tasks and demands of life, and participation, which covers engagement in life situations meaningful to the individual). These components of functioning exist in a dynamic relationship with each other and with the contextual elements of environment and personal factors (“features of an individual that are not part of a health condition or health state” [8,p.15,9]) Fig. 1.

According to ICF terminology, *impairment* indicates reduced body function, whereas *disability* represent a noncategorical term of “difficulty in functioning at the body, person, or society level, in one or more life domains, as experienced by an individual with a health condition in interactions with contextual factors” [10,p. 1220]. In other words, *disability* results from barriers to the interaction between a person’s body functions and structures, their activities, and their participation in society as influenced by environmental and personal factors. Alternatively, one could expand the concept of disability to include any external factor (i.e., social situation) that would exclude somebody from participation. “Disability” is thus a social construct.

Patient-reported outcome is an umbrella term for any personal report of an individual’s condition that comes unfiltered from that person (including children and caregivers). Such reports directly reflect the person’s current life state in relation to their expectations and their health condition and its management, without the interpretation of these persons’ responses by healthcare professionals, parents or others [5]. PROs today are considered the criterion standard to evaluate

patients’ perceptions, and they play an important role in person- and family-centered healthcare [11]. Individuals, even children, should be able and encouraged to report autonomously on their own QoL and functioning. Children’s self-reported outcomes from the developmental age of eight years have been shown to be valid and informative [12,13].

The term *PRO* was created to meet the need to develop a terminology upon which healthcare providers and policy makers could agree. This term was chosen to move away from the unsettling confusion created by the different conceptualizations of *content* terminology such as *HRQoL* and *QoL*, discussed above, that resulted in lack of equivalence and comparability among measures titled by these terms and generated a barrier to communication and research in this field. “PRO” overcomes these conceptual problems by focusing on the *source* of information, and by emphasizing the importance of the individual’s personal perspectives and priorities when deciding about potential interventions and management [14]. However, the challenge of defining *content* (outcome) is always present.

3. Whose report, with what content, should one prefer – the child’s or the caregiver’s? The importance of perspective

Having recommended the use of PRO measures (PROMs) to evaluate the QoL and functioning of children with epilepsy, we next explore whether one should prefer using children’s self-report, caregivers’ reports of PROMs, or both. It is recognized that approximately 80% of children with epilepsy have a verbal comprehension capacity to enable them to respond autonomously to questionnaires from the cognitive developmental age of eight years [12,13].

Asking parents to rate items as they believe the child would rate them (referred to as a surrogate proxy) is a complex request that is somewhat inconsistent with concepts of PRO and QoL that are defined as being a patient’s own perceptions [15]. Yet proxy accounts have been used as either a complementary or an alternative source of information about patients. Researchers and clinicians have suggested that caregivers, particularly parents, would have sufficient objectivity to evaluate the child’s own perceptions and have often recommended their use as proxies when a respondent is too young or too cognitively impaired, immature, ill, distressed, or fatigued to respond [16]. For example, we found that plotting the difference between mother’s surrogate QoL score and her child’s score produced a bell-shaped curve with slightly lower mean values for mothers’ evaluations (there were essentially no difference between mothers’ and fathers’ evaluations), meaning that these data are not interchangeable [12].

One of the factors that may contribute to these findings is the parental levels of anxiety and depression. These levels are likely to be higher among parents with a child/youth with a chronic medical illness, and higher still if their child/youth has emotional-behavioral problems [17]. This fact is one of the reasons that informant discrepancies are some of the most consistent effects observed in clinical science, particularly in reporting mood and behavioral conditions [18]. This phenomenon has been termed the “maternal distortion hypothesis” [19].

Macleod and colleagues showed that the prevalence of youth’s mood disorders varied significantly by both informer and setting (i.e., clinical or community) [18]. The prevalence of screened (as opposed to diagnosed) mood disorders in a child psychiatry clinic was reported by parents to be 28.6% versus 9.2% reported by the adolescents; whereas in a community setting parents reported abnormal mood in 3.1% versus 5.9% reported by the adolescents themselves [18]. Research in a population with childhood-onset epilepsy showed that screened parental depression and stress can bias or distort their judgment by scoring their children’s behavioral profiles 2–3 times worse than the children’s own account as adolescents and later as adults [20]. Related studies confirm that parents, particularly those with their own emotional problems, tend to rate their children’s behavior problems higher (worse) than the children themselves [21,22]. However, other researchers called into question the utility of attributing informant discrepancies to any

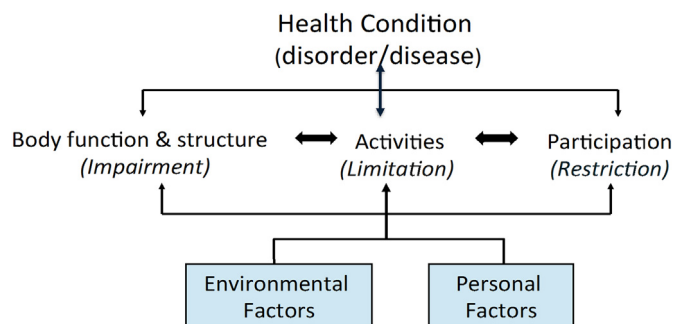


Fig. 1. The conceptual framework for the International Classification of Functioning, Disability and Health (ICF) illustrating the dynamic of biopsychosocial health [8].

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