



# The psychological costs of comparisons: Parents' social comparison moderates the links between family management of epilepsy and children's outcomes



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## ABSTRACT

Parents play a key role in how children deal with epilepsy. When diagnosed with health conditions, people seek comparison information from fellow patients and families, and this information has consequences for how they evaluate their situation. This study examined the moderating role of parents' social comparison orientation in the associations between family management (parental perceptions of family life difficulties and child's daily life) and adaptation outcomes of children with epilepsy (HRQoL and perceived stigma). Participants included 201 dyads of children with epilepsy and either their mother or father. The results showed that when parents perceived higher difficulties managing their child's epilepsy and/or reported that their child was more affected by this condition, children reported higher perceived stigma and worse HRQoL only when parents had a higher social comparison orientation. Our results are innovative in showing that when parents have a higher social comparison orientation, their children may be at increased risk of poorer outcomes.

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## 1. Introduction

Epilepsy is a heterogeneous condition in terms of presentation and severity, with seizures varying from brief lapses of attention to long lasting and severe convulsions [1,2]. Dealing with pediatric epilepsy poses significant challenges to both children and their families. The latest international recommendations emphasize the importance of directing treatment efforts toward enabling children and their families to live a life as free as possible from the medical and psychosocial complications of epilepsy [3,4]. However, even in Western industrialized countries, where most children with epilepsy benefit from appropriate antiseizure drug treatment and attain seizure control, these children are at increased risk of poor health-related quality of life (HRQoL) [5,6]. Children with epilepsy are also more vulnerable to the detrimental effects of perceived stigma [7]. Perceived stigma refers to the fear of being viewed as different from one's peers due to an undesired condition, such as epilepsy, and of being teased and bullied if a seizure occurs in front of others [7,8]; this fear ultimately affects HRQoL [9]. The development of effective psychosocial interventions to improve children's HRQoL and prevent perceived stigma is warranted. A necessary step to

achieve this goal is the identification of modifiable psychosocial factors that influence these outcomes.

Epilepsy is managed within the context of the children's family, with parents being on the front line of effective family management of children's epilepsy [10]. Monitoring children's antiseizure medication adherence, promoting healthy lifestyle behaviors, ensuring attendance of medical appointments, and providing the healthcare team with accurate information about seizures and treatment side effects are some of the daily actions included within effective family management [11,12]. For families, epilepsy may represent a significant source of stress, even long after the disease onset and regardless of seizure control status [10,13]. Despite its episodic nature, epilepsy entails ever-present threats to the physical, emotional, social, and academic domains of life of children and their families [5,14–16]. Living with epilepsy means dealing with the unpredictable nature and course of the condition; with the risk of physical injury during seizures; and with social stigma, despite the public efforts that have been made to improve awareness of epilepsy [16,17].

Although most families attempt to normalize family life and reduce the intrusion of epilepsy in their lives after the initial diagnosis crises, some struggle to accomplish this [13,18]. Challenges to family management may include restrictions in family activities and isolation [19]; difficulties attaining extended social support [15]; difficulties managing the comorbidities of epilepsy (e.g., academic and behavioral difficulties), which are often unrecognized and remain untreated [20,21]; difficulties

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working effectively with healthcare providers [20,22]; eventual changes in family roles and unwanted impact on family relationships [23]; unmet informational and emotional support needs for months to years after the diagnosis of seizure disorder [13,22]; and higher levels of psychiatric morbidity among family members [24,25].

Parents play a key role in how children's epilepsy is managed within the family, and how children with epilepsy understand and cope with their condition and the associated stigma [26]. Research shows that in some families, the concerns caused by epilepsy may be more detrimental than the disease itself (e.g., [27]). A significant percentage of parents have a negative attitude and increased apprehensiveness toward epilepsy, even when not justified by the low severity of their child's illness [28]. The pervasive belief that epilepsy is a "bad" disease is deeply rooted in parents' fears and concerns [17,28]. Despite the evidence that for most of the children affected, epilepsy entails a good clinical prognosis [29], lay people's perceptions of epilepsy are commonly attached to the dramatic presentation of generalized seizures and with the idea of chronic and incapacitating epilepsy [30]. Misunderstanding and insufficient information about the nature and consequences of epilepsy often lead parents to expect negative reactions and attitudes from others [30]. These beliefs are accompanied by negative effects on how parents respond to their children's healthcare and emotional needs, resulting in negative consequences for children's adaptation outcomes over time (e.g., [31]). Moreover, while some previous studies document stronger associations between levels of felt stigma and lower seizure control or specific seizure types (e.g., tonic-clonic) [15,26,32], other studies report that people with well-controlled [28,33] and/or focal seizures [34] experience felt stigma. It is important to note that although many types of focal seizures are relatively benign in clinical appearance, other types may be quite challenging to witness, especially if the behavior is bizarre or distressing to the individuals experiencing them (e.g., *deja vu*, illusions) [35].

From the parents' perspective, a diagnosis of epilepsy represents an ongoing source of uncertainty and threat regarding their child's actual and future health status [22,27]. Studies in the health psychology field show that in situations of increased fear and/or uncertainty, patients and their families have a need for comparison information from others who are perceived to be similar or who are facing similar life circumstances [36,37]. Parents may actively or inadvertently engage in comparison processes when waiting for their children's clinical appointments, during conversations with their children's pediatrician, when consulting internet sites and educational materials, or when talking to other parents [38]. Searching for and listening to comparison information from fellow families enable parents to evaluate their own situation (and that of their children), which ultimately may help them gain and maintain perceived control of the situation and increase well-being [38,39].

Individuals differ in their propensity to engage in social comparisons, and this personality disposition is referred to as social comparison orientation (SCO, [40]). Persons high in social comparison orientation are particularly inclined to compare their own situation and experiences with those of others [39] and are more strongly affected by social comparisons [40]. While social comparisons can increase well-being (e.g., when comparing with others who are worse off), a growing body of evidence suggests that people who spontaneously make frequent social comparisons experience more destructive emotions and behaviors [41,42]. In fact, the tendency to seek social comparison information is correlated with low self-esteem, depression, and neuroticism [40].

Despite the relevance of social comparison processes in different health contexts, the impact of parents' social comparison orientation on perceived stigma and HRQOL in children with epilepsy remains to be explored. The present study assessed a sample of 201 parent-child dyads to determine whether parent's social comparison orientation moderates the associations between parents' perceptions of family management (child daily life and family life difficulty) and their children's perceived stigma and HRQOL.

## 2. Method

### 2.1. Participants and procedures

The Board of Directors of three Portuguese public hospitals approved this study. The participants were children with epilepsy and one of their parents, and they were recruited at pediatric outpatient services. The eligibility criteria for study participation included the following: (1) a clinical diagnosis of epilepsy made by a pediatric neurologist at least 6 months prior to the study; (2) child age between 8 and 20 years; (3) absence of developmental delay or other nonneurologic conditions (e.g., asthma requiring daily medication); and (4) parent referred to as the primary care provider for health-related issues. Children with comorbid ADHD, specific learning difficulties, or behavioral or emotional problems were included because of the high prevalence of these disorders in childhood epilepsy [14]. Children with an IQ lower than 70 (according to their medical records) were excluded from the study, as were those not attending mainstream schools. Potential participants were invited to participate in the study during the children's routinely scheduled neurology appointment after a prior screening to determine whether they met the study's inclusion/exclusion criteria. Parents and children were informed that their participation was voluntary and would in no way affect the hospital care and/or level of support services their child received. Written informed consent and assent were obtained from each participating parent and child, respectively. Participants completed the questionnaires independently in a room designated for the study purposes on the day of their appointment. Children with reading difficulties received researcher assistance to complete the questionnaires. Neurologists assessed children's clinical variables at the end of the clinical visit.

### 2.2. Measures

#### 2.2.1. Family management of children's epilepsy

Parents' perceptions regarding family management of children's epilepsy were assessed with the Portuguese version of the Family Management Measure (FaMM; [43]). The FaMM is a self-report measure that addresses family caregivers' perceptions regarding dimensions of family life in the context of managing a child's chronic condition. Two specific scales were used: child daily life (five items) and family life difficulties (fourteen items). The items are answered on a five-point Likert scales ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). The child daily life scale addresses parents' perceptions of their child's everyday life (e.g., "Our child's life is similar to that of other children his/her age"). Higher scores indicate that the child lives a normal life despite their chronic health condition. The family life difficulty scale assesses parents' perceptions of the extent to which their child's condition makes their life difficult (e.g., "Our child's condition gets in the way of family relationships"). Higher scores indicate more difficulty managing the condition and a family life focused on the work/effort of managing the condition. Empirical studies support the reliability and construct validity of the FaMM [43]. In the current sample, Cronbach's alpha of the child daily life and family life difficulty subscales were .73 and .86, respectively.

#### 2.2.2. Social comparison orientation (SCO)

Parents' SCO was measured with the Portuguese version of the Iowa Netherlands Comparison Orientation Measure (INCOM, [40]), which consists of 9 items that addresses a person's social comparison habits (e.g., "I often compare how my loved ones – boy- or girlfriend, family members, etc. – are doing with how others are doing"; "I always pay a lot of attention to how I do things compared with how others do things"). Responses are provided on a 5-point scale, ranging from 1 (*I disagree strongly*) to 5 (*I agree strongly*). The higher the score is, the more the person compares him/herself with others and is affected by social comparisons. The INCOM has been shown to be a reliable and

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