



Illness perceptions determine psychological distress and quality of life in youngsters with epilepsy



Ioanna Rizou^{a,*}, Veronique De Gucht^{b,1}, Antigone Papavasiliou^{c,2}, Stan Maes^{b,1}

^a Child Psychiatry Department, Mental Health Center of General Hospital of Athens "G. Gennimatas", Athens, Greece

^b Health, Medical and Neuropsychology Department, Leiden University, Leiden, The Netherlands

^c Child Neurology Department, Pendeli Children's Hospital, Athens, Greece

ARTICLE INFO

Article history:

Received 22 February 2015

Revised 19 March 2015

Accepted 21 March 2015

Available online 19 April 2015

Keywords:

Epilepsy
Children
Adolescents
Distress
Quality of life
Self-regulation
Illness perceptions

ABSTRACT

The aim of this cross-sectional study was to explore the extent to which gender, epilepsy severity, and self-regulation concepts (illness perceptions, autonomous treatment regulation, perceived autonomy support by parents) predict psychological distress and quality of life (QoL) in young patients with epilepsy. Structured interviews were conducted in 100 patients ($M_{age} = 13.9$, $SD = 2.21$, 41% girls), and data were analyzed by means of multiple hierarchical regression analyses. Seizures of most patients (91%) were well controlled by antiepileptics, 3% of the patients had infrequent seizures, and seizures in 6% were pharmaco-resistant. At a multivariate level, it appeared that youngsters with epilepsy who expect that their disease will last for a long time, who believe that they have less personal control over their illness, and who expect the illness to have a high emotional impact reported higher levels of distress. In addition, a better QoL was reported by youngsters who believed that treatment did not control their illness and who thought that their epilepsy would not affect them emotionally. Findings indicate the importance of illness perceptions, and it is suggested that they should be targeted in future interventions in youngsters with epilepsy.

© 2015 Elsevier Inc. All rights reserved.

1. Introduction

To date, research on determinants of psychological distress and quality of life in children and adolescents suffering from epilepsy has focused mainly on: 1) disease characteristics (e.g., severity, illness duration, frequency of seizures, nature of symptoms, side effects of drugs), 2) characteristics of the adolescent (e.g., age, gender, levels of autonomy, locus of control), and 3) characteristics of the family (e.g., parenting style, problem-solving abilities) [1–5]. It is remarkable that many studies have investigated relatively stable disease, personal and family characteristics as determinants of distress, and quality of life rather than perceptions, attitudes, or skills of patients that can be more easily influenced by means of interventions [6]. For this reason, we aimed to explore, apart from demographic and disease characteristics, the role of more malleable determinants such as youngster's illness perceptions, autonomous motivation towards treatment, and parent's autonomy supportiveness on psychological distress and quality of life of youngsters with epilepsy. There is indeed increasing evidence that changing

illness and treatment perceptions has a beneficial impact on psychological distress and quality of life [6,7].

1.1. A self-regulation perspective to psychological distress and quality of life in youth with epilepsy

Psychological distress is mostly defined as a state of emotional suffering characterized by symptoms of depression and anxiety [8]. It can be considered a "normal" emotional reaction to a stressor, but can satisfy diagnostic criteria for a psychiatric disorder if accompanied by other symptoms [9]. Quality of life is defined as "an individual's perception 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, standards and concerns. It is incorporating individuals' physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationships to salient features of the environment" [10].

The above concepts are not only multidimensional, but also constantly changing. Preadolescence and adolescence are characterized by important biological, psychological, and social transitions. During these periods, independence, individuality, and freedom become increasingly important, and a chronic disease, such as epilepsy, can seriously interfere with development [1,11–15]. Youngsters suffering from epilepsy frequently report not being in control of their lives and feeling as if they have lost their freedom, leading to higher levels of depression and anxiety (psychological distress) as well as lower levels of

* Corresponding author at: 4 Agelon Street, Neo Irakleio 14121, Athens, Greece. Tel.: +30 6945461024.

E-mail address: giannarizou@gmail.com (I. Rizou).

¹ Pieter de la Court gebouw, Wassenaarseweg 52, 2333 AK Leiden, The Netherlands.

² 8 Mandelara Street, Nea Erythraia 14671, Athens, Greece.

quality of life [1,16–20]. The experience of lack of control, autonomy, and freedom can be approached from a self-regulation perspective. Self-regulation theories are centered on the idea that all behavior is goal-directed and that cognitions and skills play an important role in personal goal attainment. Illness cognitions, autonomous versus coerced regulation, and autonomy supportiveness are important concepts from this perspective [21].

1.2. Illness perceptions

Illness perceptions can be defined as patients' beliefs and expectations about their illness (or a specific symptom) [22,23]. Important attributes of illness perceptions are according to Leventhal's self-regulation theory: *identity* (the name or label given to the illness or symptoms), *timeline* (the perceived time trajectory of the illness), *consequences* (the expected future effects and outcomes of the illness), *cause* (the supposed etiology of the illness), and *cure or control* (the extent to which the patients believe that they may recover or have personal control over the illness). Finally, *emotional representations of the illness* incorporate anticipated negative emotional reactions such as anger, fear, and distress due to the presence of the disease [24,25]. Research in children and adolescents with epilepsy shows that some may be resilient and/or accepting, while others believe that everything is under control [26] or have important concerns regarding prognosis and are concerned about the consequences of poor adherence to treatment because of possible seizures [5]. Despite this, very few studies investigate their role of illness perceptions based on a solid psychological framework [26–28].

1.3. Treatment self-regulation

Self-regulation is initiated when a selection or activation of a particular goal (either conscious or unconscious) occurs. According to Deci and Ryan's (2000) Self-Determination Theory (SDT), autonomous regulation occurs when a goal is considered to be important for the person and is chosen by himself, whereas in the case of controlled regulation, other people set the goal, or there is pressure to attain this goal by external forces [21,29–31]. Research in adults suffering from various chronic diseases showed that medication adherence is positively related to patients' autonomous motivation [21,32].

1.4. Parent's autonomy supportiveness

Parenting style is of great importance to the development and wellbeing of all adolescents, but especially to youngsters suffering from a chronic illness [2,4]. Young people whose parents are less flexible and overprotective may have poorer treatment compliance and, thereby, poorer seizure control. Parents who try to give their children progressively more control over their own illness are more autonomy supportive [4,33–36]. Autonomous regulation may have beneficial consequences in terms of stress and wellbeing if the parents support autonomous regulation of the youngsters suffering from epilepsy [29].

This study explores whether, after controlling for gender and disease severity, these self-regulation constructs do explain important parts of the variance in psychological distress and quality of life in youngsters with epilepsy. More specifically, we expect that: 1) female gender and disease severity will be positively related to psychological distress and negatively related to quality of life, 2) perceptions of control will be negatively related to psychological distress and positively related to quality of life, while all other illness cognitions will show an opposite relationship, and 3) both autonomous regulation and autonomy supportiveness will be negatively related to psychological distress and positively related to quality of life.

2. Material and methods

2.1. Study design and patient recruitment

Patients were recruited from the Epilepsy Clinic of the Paediatric Neurology Department of Pendeli Children's Hospital, which treats children and adolescents with epilepsy from the Athens metropolitan area but also accepts referrals from the whole of Greece. The present study served as the cornerstone for the development of an intervention program and was approved by the Ethical Research Committee of Pendeli Children's Hospital.

Participants were recruited between March 2009 and January 2012 according to the following inclusion criteria: 1) age: 10–18 years old, 2) at least one epileptic seizure during the preceding year, 3) normal IQ, 4) no other chronic illness, physical disability, or mental disorder, 5) no surgical procedures during the preceding year, and 6) no medication change in the last 6 months.

Four hundred medical records of youngsters consecutively examined at the Epilepsy Clinic were reviewed for their eligibility for the study. After examination of the medical records by the neurologist, 200 youngsters who fulfilled the inclusion criteria were approached during their prescheduled visits.

Initially, parents were informed about the goals and procedures of the study by the treating neurologist. Subsequently a meeting with the parents and the young patient was planned to explain the study in more detail. The first 100 of them who agreed to participate signed informed consents and were included in the study. Next, all questionnaires were completed by the patient, without presence of the parents, in the context of an interview. The interviewer did not know any of the patients prior to this meeting and always asked the exact same questions of following a protocol. The interview lasted approximately 60 to 70 min.

2.2. Measures

2.2.1. Disease characteristics

Data regarding disease characteristics were derived from the medical records and included type of epilepsy, duration, age of onset, time of last seizure, total number of seizures, and medication. The severity of epilepsy was evaluated on an ordinal scale with 6 categories. Starting from the least severe epilepsy, the categories were: 1) benign focal childhood epilepsy, 2) idiopathic generalized epilepsy, 3) epilepsy well controlled by medication but with unknown prognosis (unknown etiology of epilepsy), 4) symptomatic epilepsy with adequate response to medication (more than 6 months seizure free), 5) symptomatic epilepsy with moderate response to medication (less than 6 months seizure free), and 6) pharmacoresistance (failure to respond to at least 3 appropriately selected antiepileptics) [37]. In the present study, this severity scale was used in the analyses with lower scores indicating less severe epilepsy.

All data, except for disease characteristics, were obtained by means of the following questionnaires:

2.2.2. Illness perceptions

2.2.2.1. Brief Illness Perceptions Questionnaire (BIPQ) [24]. Eight items measure cognitive illness representations (consequences, timeline, identity, personal, and treatment control) and emotional representations (concern and emotion) while there is also an item asking the patient to mention the factors that, according to his/her opinion, caused the illness. A 10-point Likert scale is used with lower scores indicating more beneficial perceptions (i.e., for timeline: 0 = my epilepsy will last for a very short time to 10 = it will last forever), except for coherence and personal and treatment control, where higher scores represent more beneficial perceptions. In order to compute the total score, the

Download English Version:

<https://daneshyari.com/en/article/6010958>

Download Persian Version:

<https://daneshyari.com/article/6010958>

[Daneshyari.com](https://daneshyari.com)