



Illness identity in young adults with refractory epilepsy

Koen Luyckx^{a,*}, Leen Oris^{a,b}, Koen Raymaekers^a, Jessica Rassart^{a,b}, Philip Moons^{a,c}, Ludo Verdyck^d, Teus Mijster^d, Ruth E. Mark^e

^a University of Leuven, Leuven, Belgium

^b Research Foundation Flanders (FWO), Belgium

^c University of Gothenburg, Gothenburg, Sweden

^d Kempenhaeghe Expertise Center Epilepsy, Oosterhout, The Netherlands

^e Tilburg University, Tilburg, The Netherlands

ARTICLE INFO

Article history:

Received 12 November 2017

Revised 30 December 2017

Accepted 30 December 2017

Available online xxxx

Keywords:

Emerging adulthood

Refractory epilepsy

Illness identity

Acceptance

Health-related quality of life

Sense of self

ABSTRACT

Introduction: Refractory epilepsy is an intrusive condition with important implications for daily functioning in emerging and young adulthood. The present study examined the degree to which refractory epilepsy is integrated in one's identity, and examined how such a sense of illness identity was related to health-related quality of life (HRQOL).

Methods: A total of 121 18- to 40-year-old patients with refractory epilepsy (56.2% women) completed self-report questionnaires assessing the four illness identity states of acceptance, enrichment, engulfment, and rejection (Illness Identity Questionnaire (IIQ)); HRQOL (Quality of Life in Epilepsy Inventory – 31); and seizure frequency and severity (Liverpool Seizure Severity Scale (LSSS)). Illness identity scores were compared with a sample of 191 patients with a nonneurological chronic disease (congenital heart disease). Hierarchical regression analyses were conducted to assess the predictive value of illness identity for HRQOL when simultaneously controlling for demographic and clinical features.

Results: Patients with refractory epilepsy scored higher on rejection and engulfment and lower on acceptance when compared with patients with congenital heart disease. Further, seizure severity and number of medication side-effects were positively related to engulfment and negatively to acceptance. Finally, when simultaneously controlling for various demographic and clinical variables, illness identity significantly predicted HRQOL (with engulfment being the strongest and most consistent predictor).

Conclusion: The extent to which patients with refractory epilepsy succeed in integrating their illness into their identity may have important implications for HRQOL. Clinicians should be especially attentive for signs that patients feel engulfed by their epilepsy.

© 2018 Elsevier Inc. All rights reserved.

1. Introduction

Epilepsy is one of the most common neurological disorders, with a prevalence rate of 6 per 1000 and a yearly incidence rate of 30 per 100,000 in European adults aged 20–64 years [1]. Although the prognosis for the majority of patients is good, up to 30% do not achieve remission despite appropriate antiepileptic drug therapy [2]. These patients with uncontrolled or refractory epilepsy often experience substantial difficulties in their individual functioning and quality of life, and bring substantial costs to society and healthcare systems [3,4]. Despite the literature testifying to the substantial impact refractory epilepsy has on daily functioning, studies on quality of life in emerging and young adults are scarce [5–7]. There has also been limited research on the impact of

refractory epilepsy on self and identity in this age-span [8]. In the present study, we introduce the concept of illness identity as a guiding framework to assess the potential impact refractory epilepsy can have on self and identity.

1.1. Emerging and young adulthood as key developmental stages

Identity constitutes a developmental construct that changes through the life-span, with most identity changes occurring in adolescence and the transition to adulthood [9,10]. However, social-structural and economic changes in Western nations have resulted in the delaying of psychosocial maturity until the mid to late twenties [9]. According to Arnett [9], emerging adulthood (ages 18 to 30 years) is the period that offers the most opportunities for identity development. Life-course events that were once normatively structured (such as marriage and entry into employment) are increasingly left to individuals to decide on their own [11,12]. Because of an expanding set of options, this emphasis

* Corresponding author at: KU Leuven, Faculty of Psychology and Educational Sciences, Tiensestraat 102, 3000 Leuven, Belgium.

E-mail address: Koen.Luyckx@kuleuven.be (K. Luyckx).

on individual free choice can induce confusion in certain young people [12,13]. This extended transitional phase can be even more challenging for youth with epilepsy [14], given that such a chronic condition represents a substantial nonnormative stressor in addition to age-specific stressors [15,16]. Individuals entering young adulthood encounter major transitions in multiple life domains and managing a neurological disorder such as epilepsy may disrupt one's life trajectory [17,18]. Research has demonstrated that young adults with childhood-onset epilepsy reported more problems with competence, agency, social relationships, and employment as compared with peers [19]. Further, emerging adults with epilepsy have been found to be more socially isolated and physically inactive [7].

Research on self and identity is scarce in emerging and young adults with epilepsy. The literature on self-concept in children and adolescents has been inconsistent [20,21]. Although it was expected that recurrent epileptic seizures, coupled with their stigmatizing nature, could compromise the development of a strong self-concept, a meta-analysis by Ferro et al. [22] failed to show that children and adolescents with epilepsy had a lower self-concept than their peers. However, previous studies mainly focused on global self-concept which does not allow for fully capturing the complexity of self and identity in individuals with a chronic illness [20]. Allebone et al. [23] focused on more specific identity processes (i.e., the degree to which individuals explore different life alternatives and make strong identity commitments; [24]) and found that adults with epilepsy scored higher on a poorly integrated or incoherent sense of self. In the present study, we extend this work by focusing on illness identity, which is defined as the degree to which chronic illness becomes integrated into one's sense of self [25,26].

1.2. Illness identity

Following Erikson [10], identity can be seen as the degree to which individuals manage to integrate different self-assets into a coherent sense of self that serves as a guidepost for daily behaviors and choices. Experiencing such self-coherence has been related to psychological well-being [27]. Hence, when confronted with epilepsy, individuals need to understand what this means to their identity and try to create or regain a coherent sense of self [28], a process originally coined as illness identity [25]. Oris et al. [26,29] have developed and validated the Illness Identity Questionnaire (IIQ) for individuals with different chronic illnesses (type 1 diabetes, congenital heart disease, and systemic disease), assessing four illness identity states: rejection, engulfment, acceptance, and enrichment. Most of these states have been suggested already in the epilepsy literature.

First, *engulfment* captures the extent to which a chronic condition dominates a person's identity. Individuals scoring high on engulfment completely define themselves in terms of their illness that invades all domains of life [30]. For patients with refractory epilepsy, this would mean that their identity gets engulfed by the illness and all defining aspects of their identity get dominated by having epilepsy [31,32]. Epilepsy becomes the only thing that the patients can think about, leading to a perceived loss of personhood [18,33]. This concept is somewhat similar to illness intrusiveness [34], referring to the disruption of personally valued lifestyles, activities, and interests due to having epilepsy.

Second, *rejection* refers to the degree to which chronic illness is rejected as part of one's identity and is viewed as a threat to the self [35,36]. Individuals try to avoid thinking about their illness and mainly resort to nondisclosure to others [36]. By neglecting their illness in daily life, patients may experience less emotional distress as compared with those patients being engulfed by their illness but, at the same time, they may display suboptimal treatment adherence [26]. In the context of epilepsy, Benson et al. [37] indicated that, in the pursuit of living a normal life, some patients rejected epilepsy as a defining aspect of their identity and strongly compartmentalized this aspect of their lives. Whether such a strategy serves a protective function or whether it results in negative consequences remains to be investigated.

Third, *acceptance* captures the degree to which individuals accept the illness as part of their identity without being overwhelmed. Chronic illness plays a peripheral role in their identity, besides other personal, relational, and social self-assets, and does not pervade all life domains [30,38]. Patients try to lead their lives as normally as possible, while at the same time, not denying they have a chronic illness [35]. During this acceptance process, individuals with epilepsy strive to maintain a sense of normality [39], that is, keep their life as congruent as possible with defining priorities and identity values they have set for themselves [37], a process also referred to as resilient integration [40].

Finally, positive changes in one's identity as a result of chronic illness have been referred to as *enrichment* [26], which is quite similar to the broader concept of benefit finding [41,42]. Whereas benefit finding captures the many ways in which such positive changes may manifest themselves (including an increased appreciation for life, changed life priorities, and more positive interpersonal relationships; [43]), enrichment specifically refers to the degree to which chronic illness enriches one's sense of self and enables one to grow as a person. Reeve and Lincoln [16] emphasized the functionality of cognitive reframing (i.e., reframing the experience of epilepsy as having positive elements as well) in coping with epilepsy. However, the notion of finding self-related benefits in the face of epilepsy remains understudied [40].

1.3. The present study

There were three main research objectives.

1.3.1. Objective 1: comparing illness identity between patients with refractory epilepsy and patients with another chronic illness (congenital heart disease)

We compared mean scores on the four illness identity states between patients with epilepsy and patients with a nonneurological chronic condition: congenital heart disease (CHD). A CHD is the most frequent birth defect (9:1000 births) and comprises a wide spectrum of structural heart lesions [44]. Although emerging and young adults with CHD generally manage to engage in different social roles, some patients may be confronted with various challenges, such as restricted employment opportunities because of physical limitations [45]. In general, however, the daily impact of CHD may be less pronounced when compared with refractory epilepsy, as the majority of patients with less severe heart lesions are asymptomatic with no lifestyle limitations [45]. We hypothesized that patients with refractory epilepsy would score lower on acceptance and higher on rejection and especially engulfment when compared with CHD [46]. Further, meta-analysis has indicated that finding benefits in confrontation with a stressor was positively related to stressor severity [41]. Hence, enrichment scores could be higher in refractory epilepsy as its intrusive nature may motivate enrichment as a way of reducing self-perceived threats [41].

1.3.2. Objective 2: linking illness identity to demographic and clinical variables in refractory epilepsy

Previous studies assessing illness identity in type 1 diabetes, CHD, and multisystem connective tissue disorders (MSD) did not find consistent associations with age and gender [26,29]. With respect to illness duration, Oris et al. [26,29] did not find significant associations with illness identity, except for a positive association with acceptance in patients with MSD. Quintas et al. [47] stated that patients with epilepsy may need some time to settle into and accept the disease and its treatment, although Staniszewska et al. [39] did not find an association between epilepsy duration and acceptance. Relatedly, Wilson et al. [8] stated that seizure onset early in life would enable individuals to incorporate epilepsy more easily into their sense of self, again suggesting that illness duration and acceptance would be positively related. Finally, we expected seizure frequency and severity to be positively related to rejection and especially engulfment and negatively related to acceptance. With respect to enrichment, we expected that experiencing more frequent and severe seizures may be related to increased attempts of

Download English Version:

<https://daneshyari.com/en/article/8683718>

Download Persian Version:

<https://daneshyari.com/article/8683718>

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