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The biopsychosocial model and quality of life in persons with active epilepsy

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ABSTRACT

Background: Despite a long recognized need in the field of the importance of the psychological and social factors in persons with epilepsy (PWE), the medical community has continued to focus primarily on seizures and their treatment (the biological–biomedical model). From the biopsychosocial perspective, a person's lived experience needs to be incorporated into the understanding of quality of life. While the biopsychosocial model has gained prominence over the years, it has not been studied much in epilepsy.
Methods: The study sample included 1720 PWE from the 2003 and the 2005 Canadian Community Health Survey (CCHS). Data were analyzed using set correlation, as it allows for the examination of the relative contribution of sets of independent variables (biological, psychological, and social domains) and a set of dependent variables (quality of life) of interest, defined as self-rated health status, self-rated mental health status, and life satisfaction.
Results: Results provide strong evidence that the full biopsychosocial model explained a significantly larger amount of variance in quality of life ($R^2 = 55.0\%$) compared with the biological–biomedical model alone ($R^2 = 24.8\%$). When the individual domains of the biopsychosocial model were controlled for, the psychological ($R^2 = 24.6\%$) and social ($R^2 = 18.5\%$) domains still explained a greater amount of the variance in quality of life compared with the biological–biomedical model ($R^2 = 14.3\%$).
Conclusions: While seizure freedom will continue to be an important treatment goal in epilepsy, the psychological and social domains are an important consideration for both interventional programs and clinical research designed to improve quality of life in PWE. Better integration of social workers and psychologists into routine care may help address these disparities.

1. Introduction

While seizure freedom is an important treatment goal in epilepsy (the biomedical model), there is growing evidence that psychosocial factors and poor mental health – not clinical variables (i.e., age at onset, seizure frequency, and side effects from antiepileptic drugs) – have the greatest impact on quality of life in persons with epilepsy (PWE) [1–4]. Furthermore, previous research has found that PWE view their main handicaps as psychological rather than purely physical and complain about a lack of counseling and support [5].

In the face of such findings, little published literature on epilepsy exists in the fields of either social work or psychology. The most recent publications underscore the association between epilepsy and psychosocial issues [6]. For example, in a clinical investigation of the association between epilepsy and depression, Zhao and colleagues found that people with epilepsy had a higher lifetime prevalence of depression; significantly more neuropsychological, psychiatric, and social impairments that limit success in education, employment, and social interactions; and significantly lower quality of life compared with individuals without epilepsy [7].

Despite the accumulating evidence in the medical profession, experts in the field acknowledge that neurologists tend to focus on the control of seizures and lack interest in psychosocial aspects of epilepsy [8]. This has led to a situation where a large proportion of PWE have remained unscreened and untreated for depression and other mental health conditions despite patients' symptoms [9–13]. This continued focus on the biomedical aspects of epilepsy (including a purely "psychiatric" view of poor mental health in PWE rooted solely in the use of psychotropic medications for symptomatic treatment) perpetuates psychosocial disparities in persons with epilepsy.

Bishop et al. argue that we need more research focusing on the associations between psychosocial problems and quality of life (QOL) [14] among PWE, especially given the profession and society's increased

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attention to health-related quality of life (HRQOL), defined as the perception of one's physical and mental health over time [15]. Health-related quality of life is also one of the priorities identified in *Healthy People 2020* [16]. In addition, the priorities emphasize HRQOL and well-being, including life satisfaction and physical, mental, and social health-related quality of life. Most importantly, these goals are consistent with social work's emphasis on a biopsychosocial model, i.e., that focuses on "… influences at multiple levels, including personal (i.e., biological and psychological), organizational and institutional, and environmental (i.e., both social and physical) …" (p. 0–25) [16].

The purpose of this research was to assess the extent to which biopsychosocial influences enhance our understanding of quality of life among PWE compared with the traditional, biomedical model that researchers and practitioners have more typically used when assessing PWE. We examined this by conceptualizing the biopsychosocial model based on its articulation in the *NASW (National Association of Social Work) Standards for Social Work Practice in Health Care Settings*. Social workers historically have used a biopsychosocial model, which emphasizes the interaction between biological and social influences on people's well-being and their mental and physical health. This model "…recognizes that health care services must take into account the physical or medical aspects of ourselves (bio); the emotional or psychological aspects (psycho); the sociocultural, sociopolitical, and socioeconomic issues in our lives (social); and how people find meaning in their lives (spiritual)" (p. 9) [17].

We used set correlation analyses to test this model, given that our focus is not on which individual variables are associated with quality of life. Instead, we sought to empirically demonstrate the explanatory advantages of a biopsychosocial model compared with a strictly biological–biomedical model. We argue that by including biopsychosocial variables in traditional, biomedical models examining quality of life among PWE, we will explain more of the variance in quality of life. We add to the biomedical model by taking into account self-rated health status, self-rated mental health status, and life satisfaction, all of which have been used in previous studies of quality of life in PWE [18–20].

Consistent with our focus on subjective perceptions of quality of life reflecting contemporary discussions about patient-centered care and perspective (PCORI), self-report measures, including self-rated health status and self-rated mental health status, were used. Successful treatment for PWE should also take into account social and psychological functions [21], as these are critical to a more holistic approach to practice [22].

We strengthen the knowledge base on quality of life among PWE by using a community sample in this investigation. The current epilepsy literature on poor mental health has primarily come from clinical populations [1,23,24]. Such studies are based on small samples and are biased by the refractory nature of the seizures in PWE seen in tertiary academic hospital settings. Clinical samples also have limited external validity, especially for addressing the wider issues of PWE in the general population. Clinicians, especially neurologists and epileptologists who treat PWE, typically focus most on seizures and their treatment (the biological–biomedical model). We expect, however, that a model that considers psychological and social factors (the biopsychosocial model) will better explain quality of life for PWE.

2. Methods

2.1. Research design

We used secondary data from the Canadian Community Health Survey (CCHS), a cross-sectional survey that collects information related to health status, health-care utilization, and health determinants to examine our model. Despite excluding some populations (individuals living on Indian Reserves, the Crown Lands, institutionalized residents, full-time members of the Canadian Forces, and residents of certain remote regions), the CCHS covers approximately 98% of the Canadian population. We combined two waves of the survey data from Statistics Canada – the 2003 CCHS 2.1 (n = 134,072, 85% response rate) and the 2005 CCHS 3.1 (n = 132,221, 79% response rate) – that allowed us to examine a rare population [25] such as those with epilepsy.

2.2. Participants/sampling

The CCHS data are based on interviews with respondents 12 years of age or older residing in households in all provinces and territories. For administrative purposes, the CCHS divides the 13 provinces in the country into 136 health regions where each territory is designated a single health region [26]. Provinces with larger populations are broken down into a number of health regions. The multistage sampling allocation strategy that was employed provided relatively equal importance to health regions and provinces. The CCHS used three sampling frames to select the sample of households: 49% of the sampled households came from an area frame (a list of geographic regions based on the Labor Force Survey), 50% came from a list frame of telephone numbers, and the remaining 1% came from a random digit dialing (RDD) telephone number frame. For the majority of health regions, 50% of the sample was selected from the area frame and 50% from the list frame of telephone numbers. As part of the process of estimation in the population surveys, weighting was applied to the survey. This procedure reflects that each person in the survey represents, besides themselves, several other persons not in the sample. In order for estimates produced from survey data to be representative of the covered population, survey weights were incorporated in the calculations.

There were a total of 1702 epilepsy cases in the combined CCHS 2.1 and CCHS 3.1 samples (see Table 1; n = 835 from the CCHS 2.1 (2003 wave) and n = 867 from the CCHS 3.1 (2005 wave)). No statistically significant differences were found for any variables based on nonoverlapping 95% CIs between the CCHS 2.1 wave and the CCHS 3.1 wave. Consistent with previous investigations, there were also no clinically meaningful differences (a level or magnitude suggesting practical relevance or a change in case definition) between each of the CCHS survey cycles before combining the results of the two consecutive surveys [27].

The diagnosis of epilepsy was assessed in the CCHS as part of a list of twenty-seven chronic medical conditions. Respondents were asked "Now I'd like to ask you about certain chronic health conditions which you may have. We are interested in 'long term conditions' that have lasted or are expected to last six months or more that have been diagnosed by a health professional". After being given a list of several conditions, respondents were asked "Do you have epilepsy?" A recent U.S. study of self-reported epilepsy in New York City used a similar method of case ascertainment and yielded a positive predictive value for epilepsy of 81.5%. The inclusion of seven more questions about seizures captured only a very small number of additional epilepsy cases but at the expense of many more false positives and a very low positive predictive value of 28% [28]. This percentage is comparable with the accuracy of an epilepsy diagnosis from administrative hospital records based on ICD-9 coding which has a positive predictive value of 84% when the code for convulsions is included [29].

The case definition for epilepsy in the CCHS did not assess timing or frequency of seizures; however, the nature of the question, as it is presented in the present tense, is thought to identify persons who perceived themselves as having seizures or not being seizure-free around the time of the survey and, therefore, are considered to have active epilepsy [30]. This case definition has been used in other Canadian surveys and yielded point prevalence estimates consistent with the rate of active epilepsy found in other epidemiological surveys using various case definitions and ascertainment methods [31,32].

We organized our independent variables in accordance with our biopsychosocial conceptual model to assess the relative contributions of biological–biomedical, psychological, and social variables in explaining our outcome measures representing quality of life among PWE. We operationalized our dependent variables using a set of quality-of-life