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

Dissertation

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By

John O. Elliott, MPH

Graduate Program in Social Work

The Ohio State University

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Dissertation Committee:

Virginia Richardson, Advisor

Alvin Mares

Bo Lu

Lisa Raiz

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Abstract

Persons with epilepsy (PWE), the most prevalent chronic neurological disease, view their main handicaps as psychological rather than purely physical. Despite a long recognized need in the field of the importance of the psychological and social factors in PWE there is still a paucity of research in the fields of psychology and social work. The medical community has continued to focus primarily on seizures and their treatment (the biological-biomedical model). Such an approach works to further perpetuate psychosocial disparities by excluding the patient's subjective viewpoint. From the biopsychosocial perspective, a person's lived experience needs to be incorporated into the understanding of health and quality of life. While the biopsychosocial model has gained notoriety over the years, it has not been studied much in epilepsy. Because the scarce research is insufficient to answer these questions further research was needed. I posed two broad questions: *1) Is quality of life in PWE better explained by the biopsychosocial model than the biological-biomedical model?* and *2) Does use of mental health services (social workers/counselors and psychologists) have a moderating effect on quality of life in PWE?*

The study used a sample of 1,720 PWE, over the age of 12, who participated in the 2003 and 2005 Canadian Community Health Survey (CCHS). Data were analyzed using set correlation, as it allows for the examination of a set of independent variables (the biological, psychological and social domains) and set of dependent variables. The

quality of life outcomes of interest (self-rated health status, self-rated mental health status and life satisfaction) were global subjective assessments applicable across different disease states.

The results provided strong evidence that the full biopsychosocial model explained a significant larger amount of variance in quality life than the biological-biomedical model alone. When the individual domains of the biopsychosocial model were controlled for, the psychological and social domains still explained a greater amount of the variance in quality of life than the biological-biomedical model. The use of mental health professional services in past 1 year did not demonstrate a moderating effect on quality of life.

While seizure freedom will continue to be an important treatment goal in epilepsy, my research suggests the psychological and social domains are an important consideration for both interventional programs and clinical research designed to improve quality of life in PWE. My findings support both previous research and the 2012 Institute of Medicine (IOM) report *Epilepsy Across the Spectrum: Promoting Health and Understanding* which has continued a call for treating the whole person – not their seizures alone. Study limitations and implications for future research are discussed.

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Vita

- 1990 AA, Information Science, Bucks County Community College
- 1992 BSBA, General Management, Shippensburg University
- 2005 MPH, Community Health Education, Temple University

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Fields of Study

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Chapter I: 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 of onset, seizure frequency and side effects from anti-epileptic drugs) have the greatest impact on quality of life in persons with epilepsy (1-4). Furthermore, previous research found persons with epilepsy (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.

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 psychiatric aspects of epilepsy (6). Psychological or social issues have received even less attention in the biomedical domain. This has led to a situation where a large proportion of PWE remain unscreened and untreated for depression and other mental health conditions despite patients' symptoms (7-11).

A 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) works to further perpetuate psychosocial disparities in persons with epilepsy. In the biomedical model, the causes, diagnosis, prognosis, treatment and outcomes of disease are largely based on physical or somatic

components (12). For PWE, successful treatment should also take into account social and psychological function (13). While the biopsychosocial model has gained notoriety over the years, it has not been fully integrated into health care or translated into a comprehensive understanding of disease and recovery (14) especially in PWE. Because the scarce research is insufficient to answer these questions further research is needed.

For this research I planned to conceptually test the biopsychosocial model through two research questions: 1) *Is quality of life in PWE better explained by the biopsychosocial model than the biological-biomedical model?* and 2) *Does use of mental health services (social workers/counselors and psychologists) have a moderating effect on quality of life in PWE?*

In an exhaustive search of the existing population data sources, the Canadian Community Health Survey (CCHS) was the only population-based data available that would allow for an examination of these issues. Other population studies such as the California Health Interview Survey (CHIS) and the Behavioral Risk Factor Surveillance System (BRFSS) have not included the range of psychological and social factors, outcome variables and health services use contained in the CCHS.

I examined quality of life outcomes in epilepsy (represented by self-rated health status, self-rated mental health status and life satisfaction) through set correlation. Set correlation allows for the testing of the individual biological, psychological and social components of the model as well as the use of multiple dependent variables. Set correlation also provides, via standardized beta weights and partialling (a procedure that controls for the independent variables in each domain), a greater understanding of individual quality of life domains and the variables that best explain them in PWE.

The *biological* domain was represented by age, gender, diagnosed comorbid somatic conditions and the number of family doctor/primary care visits in the past one year, see Figure 1. The *psychological* domain was represented by the diagnosis of a mood and/or anxiety disorder and self-perceived life stress. In addition, the psychological domain was represented by use of mental health services (number of visits to a social worker/counselor and/or psychologist in the past one year). The *social* domain was represented by key socio-demographic factors (education, employment, annual income and marital status) and sense of belonging to the community.

This study is an important step in understanding quality of life in epilepsy from a population perspective. Despite a long recognized need from experts in the field as well as national public health organizations such as the Centers for Disease Control (15) there have been very few studies of mental health services use in PWE. This study may in turn influence the methods of measuring quality of life in future epilepsy research. It may also help the medical field move closer to truly integrating social workers and psychologists into the care of PWE. Social workers provide a key understanding of the individual in their environment. In addition the fields of social worker and psychologists provide a wealth of evidence-based practice approaches that are appropriate for the needs of PWE.

Figure 1. CCHS variables representing the biopsychosocial model and quality of life

Chapter II: Literature Review

Epilepsy is a medical condition that involves episodes of irregular electrical discharge in the brain. These events can result in a periodic sudden loss or impairment of consciousness or seizures. The broad operational definition of epilepsy is based on the occurrence of two or more unprovoked seizures separated by at least 24 hours (16). Epilepsy is the fourth most common neurological disorder in the after migraine, stroke and Alzheimer's disease (17). It affects men and women of all ages, all socioeconomic backgrounds and race or ethnicities who live in all areas of the United States and across the globe (18). The most common causes of epilepsy are brain injury, stroke, central nervous system infection or brain tumor (19). Epilepsy comprises a spectrum of more than 25 different syndromes (20) and affects over 2 million people in the United States, 250,000 in Canada and 65 million people worldwide (18, 21). Direct medical care costs for epilepsy are estimated between \$9.6 billion and \$12.5 billion per year in the United States (22, 23).

The overall incidence of epilepsy is approximately 50/100,000 per year and has a bimodal distribution by age (highest incidence rates are for children below five years of age and adults over age 65) (24). Overall prevalence (total number of cases any time point) is estimated between 5–10 per 1,000 (24). Despite impacting a large number of people, epilepsy has only been recognized as a public health concern in the past 15 years

(15, 25). According to Trevathan (2010) public health researchers, policy makers and advocates are “flying blind” due to a lack of adequate epilepsy surveillance data (26).

Clinically, the goal for most epilepsy practitioners remains “no seizures and no side effects” (27) and with proper medical treatment, seizures can be controlled in approximately 70% of cases (28). However, between 30-35% of persons with epilepsy are not controlled through antiepileptic drugs (AEDs) (29, 30) and continue to experience seizures despite the availability of over 35 different seizure medications since 1910 (18).

While seizure freedom is an important treatment goal there is growing evidence that poor mental health is more significant than seizures in terms of quality of life outcomes:

“Most of the medical literature on epilepsy is written from the viewpoint of the healthcare professional and this is often reflected in the way patients are managed. While seizure control is the overriding goal of treatment for both clinicians and patients, success for patients with epilepsy extends beyond seizure freedom” (p. 9) (13).

Over 50 years ago it was suggested that epilepsy treatment go beyond purely a biomedical focus of medication and surgery to a biopsychosocial one that also integrates the physical, mental and social aspects of health:

“The good physician is concerned not only with turbulent brain waves but with disturbed emotions and with social injustice, for the epileptic is not just a nerve-muscle preparation; he is a person, in health an integrated combination of the physical, the mental, the social and the spiritual. Disruption of any part can cause or aggravate illness” (p. 1690) (31).

A call to go beyond the biomedical approach was also elucidated in the epilepsy surgery literature by Penfield and Paine in 1955:

“It is not enough to know whether a radical surgical procedure has stopped attacks or not. We must know its effect upon the patient's ability to work, to hold a job, to study; the effect on physical and mental function, the effect on behavior and on

the happiness of the patient and friends. When all the features of his life are considered, it still remains for the physician to ask the final question: In the opinion of the patient and of those who love him, was the operation a success or failure?" (32).

This interplay between chronic disease and biopsychosocial factors in epilepsy has continued to be recognized over the years. The 1978 report *Plan for Nationwide Action on Epilepsy* stated "possibly the least understood and most neglected aspects of epilepsy are the social, psychological and behavioral problems that are so common" (33).

The more recent literature has continued to suggest epilepsy treatment focus on broad strategies that addresses the needs of the whole person (34) by taking into account social, vocational and psychological function (13). Such an approach is consistent with the biopsychosocial model:

"Most people with epilepsy can live outwardly normal lives, but fear about impending seizures, driving restrictions, lack of independence, employment and social problems, medication-related adverse effects and the presence of cognitive or psychiatric complications are all concerns readily identified by affected individuals" (p. 3) (13).

"Seizures are clearly the primary symptom of epilepsy, but in many cases they are only the tip of the iceberg. Treating the whole patient requires looking for hidden concerns and comorbidities, aspects of epilepsy that can be discovered only by clinicians who take the time to look for them" (p. 21) (34).

The 2003 "Living Well with Epilepsy II" conference held in conjunction with the American Epilepsy Society, the Centers for Disease Control and Prevention (CDC), the Epilepsy Foundation and the National Association of Epilepsy Centers focused on four major areas: 1) early recognition, diagnosis and treatment, 2) epidemiology and surveillance, 3) self-management and 4) the impact of epilepsy on quality of life (15).

The report called for surveillance systems that "address critical issues for people with epilepsy, including the burden of disease, mortality risks and a firmer picture of its

incidence and prevalence, particularly in special populations" (p. 5) (15). This included expanded research on comorbid conditions and epilepsy. The priority recommendations under quality of life included 1) establish standards of care for mental health issues, 2) increase availability of mental health assessments and treatment at comprehensive epilepsy centers and 3) improve access to psychiatric care by building bridges between the mental health and epilepsy communities (p. 24) (15).

Most recently the Institute of Medicine published the 2012 report *Epilepsy Across the Spectrum: Promoting Health and Understanding* that highlighted similar goals: 1) validate and implement standard definitions and criteria for epilepsy case ascertainment, health care and community services use and costs, and quality-of-life measurement, 2) continue and expand collaborative surveillance and data collection efforts, 3) develop and evaluate prevention efforts for epilepsy and its consequences, 4) improve the early identification of epilepsy and its comorbid health conditions, 5) develop and implement a national quality measurement and improvement strategy for epilepsy care, 6) establish accreditation of epilepsy centers and an epilepsy care network, 7) improve health professional education about the epilepsies, 8) improve the delivery and coordination of community services, 9) improve and expand educational opportunities for patients and families, 10) inform media to improve awareness and eliminate stigma, 11) coordinate public awareness efforts, 12) continue and expand vision 20-20 working groups and collaborative partnerships among epilepsy groups and 13) engage in education, dissemination, and advocacy for improved epilepsy care and services (18). Of these 13 goals, eight (1, 2, 7, 8, 9, 10, 11 and 13) are relevant to the focus and implications of my research.

Despite the IOM recommendations and numerous studies examining the neuropsychiatric components of epilepsy and the resulting psychosocial issues, most medical-based tertiary epilepsy centers in North America do not provide comprehensive intervention programs that address the psychosocial, educational, vocational and family support needs of persons with epilepsy (PWE) and their families (35). In particular, focused psychosocial interventions are important to improving quality of life in PWE however to date only a small number of investigations have been conducted.

Research questions

Since clinicians, especially neurologists and epileptologists, who treat PWE continue to focus almost solely on seizures and their treatment (the biological-biomedical model) it would be valuable to examine if a model that also takes into account psychological and social factors (the biopsychosocial model) would better explain quality of life in PWE.

Furthermore, the clinical literature suggests that quality of life in PWE may be moderated by the use of mental health services; however research in this area has been very limited. The current epilepsy literature on poor mental health has primarily come from clinical populations (1, 36, 37). Such studies are based on small samples and are biased by the refractory nature of 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. Because the scarce research is insufficient to determine whether treatment for PWE with poor mental health is effective, further research is needed. Therefore, I plan to conceptually test the biopsychosocial model by asking two broad questions:

- 1) *Is quality of life in PWE better explained by the biopsychosocial model than the biological-biomedical model?*
- 2) *Does use of mental health services (social workers/counselors and psychologists) have a moderating effect on quality of life in PWE?*

In an exhaustive search of the existing population data sources, the Canadian Community Health Survey (CCHS) is the only population based data available that would allow for an examination of these issues. Furthermore, previous examinations of the epilepsy in Canada have focused on establishing prevalence rates (38-42) and have not examined quality of life.

Conceptual Literature Review

Health

The World Health Organization (WHO) defined health in 1946 as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (p. 1315) (43). Theoretically, this leads to a discussion of the differences between disease, illness and wellness. Disease represents "an objective and definable process characterized by pathophysiology and pathology" as where illness is "the subjective experience of a disease state" (p. 6) (44). Wellness, on the other hand, has been defined as "an integrated method of functioning, which is oriented toward maximizing the potential of which the individual is capable" (p. 4) (45).

Quality of Life

No description of health is complete without reference to quality of life which has been defined by the WHO as:

“...an individuals’ 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 a broad ranging concept, incorporating in a complex way individuals’ physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment. This definition highlights the view that quality of life is subjective, includes both positive and negative facets of life and is multi-dimensional” (p. 1405) (46).

Overall, these definitions suggest quality of life is related to health but also distinct from it. Quality of life has many interpretations and little agreement has been attained: “The concept of quality of life is not defined in a uniform way, lacks clarity and even creates confusion” (p. 3) (47). Common definitions include: health status, physical functioning, symptoms, psychosocial adjustment, well-being, life satisfaction, happiness, subjective well-being, health perceptions, needs satisfaction, individual cognition, functional disability and psychiatric disturbance (48-51).

Health-related quality of life (HRQOL)

As an extension of the quality of life concept arose the term health-related quality of life (HRQOL) which appeared in the literature in the early 1980’s (52). In this early context, HRQOL was thought of in terms of “number of well-years”. The purpose was to determine a cost-utility ratio that would assess the contribution of different programs in the health care system as well as number of life years adjusted for lost quality due to disease or disability (52). More recently, health-related quality of life (HRQOL) has been defined as “the functional effect of an illness and its consequent therapy on a

patient, as perceived by the patient” (53). HRQOL was intended to narrow down the focus on the effects of health, illness and treatment on quality of life (51).

HRQOL is assumed to be a broad multi-dimensional construct that refers to the aspects of life that reasonably relate to health (54). The most frequently used dimensions include physical functioning, symptoms, global judgments of health, psychological well-being, social well-being, cognitive functioning, role activities, personal constructs and satisfaction with care (55). In the epilepsy literature HRQOL has included physical, psychological and social well-being as well as independent living, work and transportation issues (53).

HRQOL involves the subjective experience of well-being across social and emotional dimensions, as well as general health (1). Multidimensional HRQOL scales however have been criticized for being used in an atheoretical context. This prompted the development of specific models (49). Wilson and Cleary’s HRQOL model, in particular, led to a call for more theoretical approaches and mediational models of quality of life (56, 57).

Quality of life instruments: disease-specific versus generic

Disease-specific instruments have also been developed with the intention of focusing on a particular disease, or a narrow range of diseases, and are useful for clinical trials or outcomes assessments (58). In the epilepsy fields several domain specific instruments have been developed. The most studied of these is called the Quality of Life in Epilepsy Inventory (QOLIE-89). The QOLIE-89 focuses on representing the multiple dimensions of health-related quality of life specific to PWE. The QOLIE epilepsy-specific measure is based primarily on the Medical Outcomes Study 36-Item Short Form

(SF-36), a multidimensional survey based on functional health and well-being scores (59).

The QOLIE-89 includes health perceptions, overall quality of life, physical function, role limitations-physical, role limitations-emotional, pain, working/driving/social function, energy/fatigue, emotional well-being, attention/concentration, health discouragement, seizure worry, memory, language, medication effects, social support, social isolation, change in health, sexual relations and overall health (60). One of the primary drawbacks to the QOLIE-89 is its length. This prompted the development of two shorter instruments the QOLIE-31 and the QOLIE-10. Furthermore, it is not practical to use disease-specific quality of life instruments such as the QOLIE in epidemiological studies such as the CCHS. Epidemiological surveys are expensive to plan and administer necessitating a focus of broad questions applicable to the greatest number of people.

Generic instruments on the other hand are intended to be applicable to a wide range of health issues. This broad perspective is intended to be applicable across different disease states, treatments and interventions (58). One primary criticism of quality of life research has been its over concern with measurement issues and psychometrics at the expense of theoretical or conceptual components (47). To improve quality of life measurement in future studies, Gill and Feinstein recommended the use of at least two global ratings, one to assess overall quality of life and the other to assess HRQOL (48).

Objective versus subjective measurement of quality of life

The other debate in the quality of life literature has focused on the use of objective or subjective measures. Three primary ways of measuring health are reported in the literature. Two focus on objective measures such as the occurrence of disease (often from a "negative" perspective such as morbidity or mortality) and functioning health status (effect of illness and its therapy on a patient). The third focuses on measuring subjective perceptions of health (50). Angel and Gronfein (1988) consider subjective self-reports (such as well-being, general health, attitudes or pain) to have no objective external reference. In the objective realm they refer to reports such as income, arrests or hospitalizations as referring to some objective external reality (61).

The CDC has recommended “for scientific credibility” that HRQOL measures include observable, quantifiable phenomena such functional impairments as well as subjective qualitative information such as perceived health status (62). It has however been recognized that objective reports can be also “wrong” due things such as memory loss. Subjective states, on the other hand, cannot be “wrong” in the same sense since individuals are “by definition, the only judges of what constitutes happiness, satisfaction, health, etc” (p. 465) (61).

Subjective ratings are based on the idea that individuals must be allowed to be judges of their own experience and that “people are understood to be active agents who are involved in a continuous search for meaning in their lives” (p. 482) (54). It is an insider perspective rather than an outsider perspective:

“We are talking about aspects of people’s experience that are not directly available to external observers, e.g. individual’s beliefs, goals and values reflecting their cognitive experience and their feelings and moods reflecting their affective experience” (p. 482) (54).

A key call to focus on the subjective aspects of quality of life can be found in Clancy and Eisenberg's 1998 article in the journal *Science* that stated: "outcomes research - the study of the end results of care that takes patients' experiences, preferences, and values into account - is intended to provide scientific evidence relating to decisions made by all who participate in health care"(63). Recent studies have continued to recommend that service user's views be taken into account when selecting measures to evaluate treatment outcomes, especially in the area of mental health services (64). Furthermore, subjective quality of life measures are strongly associated with both objective physical and mental health status (62, 65-67).

Despite interest in quality of life in many other chronic diseases, only within the past 20 years has the term "quality of life" formally appeared in the epilepsy literature (68).

"As practitioners, we are often struck by the unique inner strength and success of some patients who are able to achieve personal success and life satisfaction where others fail despite repeated attempts at support and intervention. Understanding the factors that help build internal and external resources for dealing with adversity in epilepsy is critically important so that we can become better able to promote and support resilience, resourcefulness and courage in people living with epilepsy" (p. S21) (35).

For this study, quality of life was conceptualized as self-rated health status, self-rated mental health status and life satisfaction (see Figure 1). These measures address the importance of using subjective assessments to assess quality of life. As generic measures they also allow for comparisons across various chronic diseases and health conditions which are often the focus of population-based epidemiological research. The three chosen measures are broad in nature, while capturing different aspects of health (self-rated health status and self-rated mental health status) and include a global measure of

quality of life (life satisfaction) and are therefore consistent with approaches called for in the literature (48).

Self-rated health status

The first component of the WHO definition focuses on overall health. Self-rated health has been defined as an individual's perception of his or her overall health or well-being (69, 70). Self-rated health reflects the degree to which people are satisfied with their health and whether they can perform their usual activities (71). As a self-reported subjective health measure, self-rated health status reflects “a person’s integrated perception of health, including its biological, psychological and social dimensions, that is inaccessible to any external observer” (p. 517) (72). Some investigators have however suggested self-rated health status more reflects physical health (73) (i.e., limitations in physical functioning and chronic or acute conditions) over mental health problems (74).

Global ratings of self-rated health status (which only takes seconds to obtain) were found to be an independent predictor of mortality in 27 community-based studies, despite numerous health status indicators and other covariates that predict mortality (75). The authors suggest respondents’ self-rated health status are holistic, include information on medical status but that such information is evaluated differently by men and women in different social positions, with different reference groups for social comparison (75).

Possible explanations of the association between self-rated health status and mortality include: 1. self-rated health is a more inclusive and accurate measure of health than the risk factors or covariates, 2. self-rated health captures the full array of illnesses a person has and possibly those not presently diagnosed or in the preclinical stage, 3. self-rated health status represents a complex human judgment about the severity of illness, 4.

self-rated health status reflects family history, 5. self-rated health is a dynamic evaluation that also takes into account a judgment of the trajectory of their health, 6. self-rated health influences behaviors such as physical activity that subsequently impact health status, 7. poor self-rated health status may lead to less engagement in preventive behaviors, 8. poor self-rated health may influence non-adherence to screening and medical treatments, 9. self-rated health reflects presence or absence of resources that impact decline in health, 10. self-rated health may reflect the adequacy of resources to meet future health needs not just the absolute level and 11. self-rated health may reflect within-person resources (p. 27-30) (75).

Self-rated mental health status

The second component of the WHO definition focuses on mental health. Self-rated mental health status has been defined as a measure of general mental health (76). Self-rated mental health is distinct in that it measures mental health versus mental illness (77). Rather than seeking to assign a clinical diagnosis, self-rated mental health reflects the respondent's perceptions of their own mental health. In addition, perceived or self-rated mental health is thought to be "inherently valid because the respondent is the best judge of his or her own perceptions" (p. 439) (77).

Self-rated mental health status addresses the limitations of self-rated health status as being primarily a measure of physical health (74). Prior research found that self-rated mental health was not equivalent to symptoms of anxiety or depression (78) and therefore may explain variations in mental health services use after controlling for symptoms (79).

Population surveys have reported that a majority of people with mental disorders do not receive treatment from mental health professionals (78). Self-rated mental health

status ratings have been found to be strongly associated with psychotropic medication use; excellent (reference Odds Ratio = 1), very good OR = 1.84 (standard error SE = 0.11), good OR = 3.02 (SE = 0.20), fair OR = 5.27 (SE = 0.45) and poor OR = 9.36 (SE = 1.37) as well as mental health services use; excellent (reference =1), very good OR = 2.76 (SE = 0.31), good OR = 5.20 (SE = 0.57), fair OR = 12.34 (SE = 1.66) and poor OR = 20.75 (SE = 3.77) (78). Self-rated mental health was also significantly associated with the purchase of mental health medications and ambulatory mental health visits after controlling for symptoms of anxiety and depression (78).

In an examination of self-rated mental health status in the 2002 CCHS 1.2 survey researchers found a gradient for fair/poor self-rated mental health based on how recent a psychiatric episode was reported using the World Mental Health version of the Composite International Diagnostic Interview (WMH-CIDI), an instrument based on definitions in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) (76). The gradient was apparent in those with a WMH-CIDI measured disorder in the past month compared to those with a disorder in the past 2 to 12 months, those with a lifetime history of a disorder and those who had never had a disorder. For the overall measure of any WMH-CIDI disorder, the prevalence of fair/poor mental health was 45% (OR = 11.2, 95%CI: 9.1-13.9) for those who reported a mental health episode (depression, bipolar disorder or anxiety) in the past month compared to those with a disorder in the past 2 to 12 months of 27.4% (OR = 6.3, 95%CI: 5.2-7.7), those with a lifetime history of a disorder of 10.1% (OR = 2.4, 95%CI: 2.0-2.8) and those who had never had a disorder of 3.5% (reference group = 1).

For persons with multiple disorders, the proportion who reported fair/poor mental health was 73.4% (OR = 37.3, 95%CI: 22.9-60.8) for those who reported a mental health episode (depression, bipolar disorder or anxiety) in the past month compared to those with a diagnosed mental health disorder in the past 2 to 12 months of 38.5% (OR = 6.8, 95%CI: 4.7-9.7), those with a lifetime history of a disorder of 15.2% (OR = 2.6, 95%CI: 2.0-3.5) and those who had never had a disorder of 5.7% (reference group = 1). The odds ratios are based on models that adjusted for socio-demographic (gender, age, marital status, education, household income and immigrant status) and physical health characteristics (chronic condition yes/no) (76).

In previous population surveys fair or poor self-rated mental health status was predictive of mental health services use compared to those with excellent or very good self-rated mental health status, after controlling for the specific mental health conditions (80). In the National Comorbidity Survey persons with fair or poor self-rated mental health were more likely to have a perceived need for mental health services (44.8%) compared to those with good (23.9%) or those with excellent/very good self-rated mental health (14.6%) (80). Persons with fair or poor self-rated mental health were 2.7 times more likely to use health services for a mental health problem in the U.S. and 5.0 times more likely in Ontario (80).

In the CCHS cycle 1.2, the prevalence of fair/poor self-rated mental health status was highest among those with an episode of depression, bipolar or anxiety (using the WMH-CIDI instrument based on DSM-IV-TR) in the past 2 to 12 months. Among those with a mental health diagnosis, the overall proportion who reported fair/poor self-rated

mental health status was 46% compared to 6% in those who had not reported a mental health diagnosis (76).

Life Satisfaction

Based on the WHO definition of quality of life as “the perception of individuals of their position in life, in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (81), life satisfaction is also a global assessment of quality of life. Shin and Johnson (1978) define life satisfaction as a global assessment of quality of life according to a person’s chosen criteria (82). Life satisfaction may also relate to one’s life circumstances (83). These definitions of life satisfaction suggest that people examine the tangible aspects of their lives while weighing the good against the bad to determine a judgment of overall satisfaction (84).

Life satisfaction encompasses physical, mental and social aspects and is a judgment of satisfaction based on a comparison with a standard that individuals set for themselves (85). Life satisfaction refers to a cognitive judgmental process (85) where individuals provide a global assessment of how and why they experience life in positive ways (interest in life, happiness, loneliness, ease of living, well-being and life success) (86, 87).

General measures of life satisfaction or happiness are not strongly related to objective life circumstances and lower levels of functioning are not always related to low levels of satisfaction (49). This may reflect the fact that people's expectations are based on changes in life circumstances. While the terms life satisfaction, happiness, well being and quality of life are often used interchangeably it has been argued that quality of life

relates to a person's functional status and this can be measured both objectively and subjectively (49). Life satisfaction on the other hand deals only with the subjective aspect (88). The need to assess an overall rating of life satisfaction, rather than summing across their satisfaction within specific domains has been recommended; "happiness requires total satisfaction... that is satisfaction with life as a whole" (85).

In a nationwide sample of adults age 18-64 from the Finnish Twin Cohort (a 20 year prospective study) poor life satisfaction (defined by interest in life, happiness, loneliness and general ease of living) was linearly associated with increased all-cause mortality, age-adjusted hazard ratio (HR = 2.11, 95%CI: 1.68-2.64), disease mortality (HR = 1.83, 95%CI: 1.40-2.39), injury mortality (HR = 3.01, 95%CI: 1.94-4.69), (86) and suicide, age-adjusted hazard ratio (HR = 3.02, 95%CI: 1.83-4.98) (89).

Life satisfaction has not been examined as much in epilepsy as some other chronic illnesses (90-94) despite a call for its inclusion in epilepsy-related quality of life research as far back as 1992 (68). In the recent review article *Maximizing Quality of Life in People Living with Epilepsy*, Sherman (2009) defined quality of life as "life satisfaction and subjective well-being" (p. S17) (35).

A recent Norwegian study examining life satisfaction in PWE using a one-item scale (Cantril's ladder) found those who were married or cohabitating, but did not have children, reported greater life satisfaction than people with children (95). The study also found that people living alone were the least satisfied with life and people who were in school or were employed full-time were more satisfied than those who were employed part-time or were disabled. In addition, PWE with no comorbid health conditions

reported less psychological distress and greater life satisfaction than PWE with additional comorbid conditions.

A follow up paper examined life satisfaction in PWE in the present as compared to 5 years ago. Respondents who were diagnosed less than 5 years ago perceived their life satisfaction to be reduced by almost one standard deviation, as compared to their life satisfaction before the diagnosis (96). However, one Swedish study of life satisfaction comparing 106 medically intractable persons with partial epilepsy to 200 neurologically normal controls found no difference in overall life satisfaction (97). A sub-analysis of the patients who had epilepsy surgery did however find a higher level of life satisfaction in the seizure-free group.

The biological-biomedical model

In the biomedical model, the causes, diagnosis, prognosis, treatment and outcomes of disease are largely based on physical or somatic components (12) where the focus is on etiologic agents, pathological processes and biological, physiological or clinical outcomes (49). Furthermore, the biomedical model separates the mind and body in the causation of disease and this has lead to health outcomes that are primarily driven by health professionals and the medical system with little input from the individual patient (12). Overall, this focus on pathology, to the exclusion of processes of health and recovery, has resulted in a fragmented and incomplete understanding of the person and their disease (14). Subjective human experience needs scientific study alongside and in equal importance with reductionistic, mechanistic and physical explanations of disease (98).

Biological components of epilepsy and the brain

Clinical neurology has been very successful in medicalizing the human experience of PWE. Epilepsy treatment continues to follow a biological-biomedical model where “reduction of seizure frequency is the dominant focus of neurologists’ care of epilepsy patient and is the standard endpoint of clinical trials of anti-epileptic drugs (AEDs)” (4). Blumer stated that neurologists tend to focus on the control of seizures and lack interest in “psychiatric” aspects of epilepsy (6).

While the CDC *Living with Epilepsy II* report identified key quality of life objectives for PWE, the overall focus remained strictly from the biological-biomedical perspective:

"Research is needed to identify explanations for lack of treatment so interventions can be developed to address them. Possible reasons for under-treatment include generally unfounded concerns that antidepressants will make the seizures worse, neurologists’ lack of adequate training in psychiatry, lack of reimbursement and access to providers of mental health care services, the belief that AEDs are already providing psychiatric as well as epilepsy treatment, and the fact that psychiatrists are not always interested in treating people with epilepsy" (p. 23) (15).

An extensive amount of medical research has been conducted in order to identify the biological aspects of mood and epilepsy. Temporal lobe epilepsy, in particular, is thought to affect the limbic system and subsequently influence mood (99).

Hypothalamic-pituitary-adrenal hyperactivity has also been shown to be related to the severity of depressive mood symptoms (yet independent of recurrent seizures) (100).

The pathophysiology of depression is evident in frontal and temporal lobe dysfunction in PWE, as well as in research showing alterations in neurotransmitters (such as serotonin, norepinephrine, GABA, dopamine, and glutamate) (101, 102). Albano and

colleagues, based on a small interventional study, suggested dysfunction of the serotonin system may be involved in the generation of seizures (103). This is supported by data from phase II and III clinical trials of psychotropic drugs conducted in the United States between 1985 and 2004, which found that the incidence of seizures was 52% lower in people receiving antidepressants compared to those receiving placebo (104). In addition, brain specific biological components of epilepsy other biological factors such as age, gender, comorbid somatic conditions and the use of primary care are considered in the realm of the biomedical model.

Age

In the biological-biomedical model age is a significant factor in medical treatment. This is evident in the medical specialties of pediatrics and geriatric medicine. Age at epilepsy diagnosis can have a profound long-term effect across the lifespan. Incidence (new cases) of epilepsy follows a U shaped curve based on age (higher incidence rates in infants/children and older adults). Childhood onset epilepsy has been found to lead to long term complications with educational attainment and disability. Children with epilepsy are an educationally vulnerable group and educational staff need to be aware of the additional support the students may need (105).

The concerns of persons with new onset epilepsy in adulthood are different than those with epilepsy starting in childhood. New onset seizures in adulthood can trigger a complex adjustment process. One prospective study describing the psychosocial adjustment process following newly diagnosed seizures found pervasive loss of control, anxiety, and depression predicted subsequent seizure recurrence (106). In addition, cognitive problems from seizures and/or their treatment can have problematic effects on

the changing psychological and medical contexts and life adjustment to epilepsy as an adult (107).

In the elderly, stroke is the most common cause of new onset epilepsy. Seizures after an acute stroke have been estimated to occur in 5% to 10% of cases (108). A large prevalence study in the UK found few differences between older and younger people with regard to their reported quality of life, however younger people were more likely to report feeling stigmatized and PWE diagnosed in later life were more anxious and depressed than those diagnosed earlier. Their overall perception of quality of life was also more likely to be negative (109). Other literature suggests, although often under-diagnosed and inadequately treated, depression and anxiety are common in elderly persons with epilepsy (110).

Gender

Gender differences are also well recognized in the biological-biomedical aspects of clinical care. Previous research suggests while the overall incidence of epilepsy is slightly higher in males, females are more likely to have a generalized form of epilepsy (111). Several studies suggest females are more likely to be seen by a neurologist versus a general practitioner (112, 113). Despite evidence of a gender differential with regards to access to specialty care, rates of refractory epilepsy (treatment resistance seizures) are the same in both genders (114). Both genders also share a higher incidence of sexual dysfunction, however females are more likely to experience endocrine related issues from anti-epileptic drugs (AEDs) (115) which impact clinical decisions related to contraception, pregnancy, menopause and bone health (116).

The medical literature suggests gender should be included as a biological component of health in PWE. A recent Institute of Medicine report titled *Exploring the Biological Contributions to Human Health: Does Sex Matter?* highlighted the importance of understanding gender differences at the societal level based on individual behaviors, lifestyle and surroundings (117).

Comorbid somatic conditions in persons with epilepsy

In addition to the biological aspects of epilepsy and brain function, numerous studies PWE have found a higher prevalence of many comorbid somatic conditions compared to those without epilepsy. Gaitatzis and colleagues' seminal article examining the psychiatric and somatic comorbidities in over 1 million residents in the prospectively collected UK General Practice Research Database, reported large disparities in disease prevalence for PWE (118). Rate ratios of somatic disorders were significantly increased in PWE compared to the non-epilepsy population, regardless of age or gender. These included stroke (RR = 6.96, 95%CI: 6.38-7.60), Alzheimer's disease (RR = 8.05, 95%CI: 5.89-11.00), Parkinson's disease (RR = 3.19, 95%CI: 2.44-4.18), migraine (RR = 1.60, 95%CI: 1.43-1.80), heart disease (RR = 1.34, 95%CI: 1.19-1.50), heart failure (RR = 1.68, 95%CI: 1.45-1.95), diabetes (RR = 1.57, 95%CI: 1.39-1.78), asthma (RR = 1.30, 95%CI: 1.19-1.41), peptic ulcer (RR = 1.92, 95%CI: 1.55-2.37) and fractures (RR = 2.17, 95%CI: 2.00-2.35) (118). While covering a broad range of comorbid conditions, the UK study had significant limitations in that the general practitioner registries are more likely to include sicker patients.

A previous Canadian study examining prevalence of chronic health conditions in PWE compared to the general population also found high prevalence ratios for stroke (PR

= 3.9, 95%CI: 2.7-5.3), asthma (PR = 1.4, 95%CI: 1.1-1.7), arthritis (PR = 1.4, 95%CI: 1.2-1.6), heart disease (PR = 2.3, 95%CI: 1.9-2.7) and migraines (PR = 2.0, 95%CI: 1.7-2.3), but non-significant differences in rates of cancer (PR = 1.4, 95%CI: 0.9-2.1), high blood pressure (PR = 1.1, 95%CI: 0.9-1.3) and diabetes (PR = 1.2, 95%CI: 0.9-1.6) (39). Since the Canadian study was population based it was more likely to capture both healthy and sick individuals as compared to the UK General Practice data.

Based on these large cross-sectional population surveys, smaller scale data have also been reported from the United States. In the 2003 and 2005 California Health Interview Survey (CHIS), PWE reported a greater comorbid burden, especially for cardiovascular-related conditions, than those without epilepsy. In the 2005 CHIS many comorbid conditions were significantly higher (based on non-overlapping 95% CIs) in persons with a history of epilepsy; Type II diabetes, asthma, high cholesterol, heart disease, stroke, arthritis and cancer. When comorbid conditions (all of which lead to poor health status) such as asthma, obesity, Type 2 diabetes, high blood pressure, high cholesterol, heart disease, stroke and cancer are controlled for, persons with a history of epilepsy continued to have significantly poorer health status (119). These results suggest despite a greater prevalence of comorbid somatic condition in PWE, a diagnosis of epilepsy has an independent effect on quality of life.

The biopsychosocial model

In conceptualizing the biopsychosocial model in 1977, George Engel (a psychiatrist) sought to use General Systems Theory to improve the understanding of the bi-directional relationship between the body and mind, as well as to reconcile the dualist concepts that separate health and disease (120). In General Systems Theory no system

exists in isolation and every system is influenced by its environmental configuration (121). In the medical domain, Engel felt General Systems Theory provided a conceptual approach for studying the biopsychosocial approach but also for studying disease and medical care as interrelated processes (120).

Engel argued the biomedical model is a reductionistic model since it is based on a philosophical principle that complex problems can be explained at the simplest cellular level (122). For “scientific” reasons the biomedical model excludes the patient’s subjective viewpoint, the biopsychosocial model however aims to unite science and humanity (123). While to not deny that biomedical research had lead to important advances, Engel instead criticized its narrow approach that lead clinicians to regard patients as objects and for ignoring the subjective experience of the patient (98). From the biopsychosocial perspective, a person’s lived experience needs to be incorporated into the understanding of health (124).

While the biopsychosocial model has gained notoriety over the years, it has not been fully integrated into health care or translated into a comprehensive understanding of disease and recovery (14). Furthermore, the biopsychosocial model has been critically viewed as more of a construct without a formal, working representation of the idea as a “model” (125). Based on the definitions of a “theory” as a broad, general statement and a “model” as a practical way of matching a theory to reality (125), Engel has been criticized for not defining the model or specifying what the model would look like, but rather demonstrating a need for more humanity in medicine (125) and that as a model it continues to serve mostly as an unmet challenge for research (understanding the etiology and development of disease or disorder) and practice (diagnosis and treatment)(126).

While the biopsychosocial model is status quo in psychiatry, critics have argued it has “devolved into eclecticism” and that “the biopsychosocial model only shines when opposed to straw men”(127). McLaren stated:

“...unless there is an integrating theory already in place, gathering biological, psychological and sociological data about people will only yield scattered lumps of information that do not relate to each other in any coherent sense. Without an overarching theory to integrate the fields from which the data derive, associations between differing classes of information are meaningless” (p. 91) (125).

Clearly, challenges remain as models are needed that specify the processes which connect the biological, psychological and social systems (128). Suls and Rothman have suggested:

“If investigators hope to delineate the linkages between the multiple systems implicated in the biopsychosocial model, studies need to prioritize the inclusion of a diverse set of indicators....For the biopsychosocial model to be fully embraced, investigations need to continue to transform it from a conceptual framework into a model that specifies linkages between the different subsystems” (p. 121-122) (128).

The entrenchment of the biomedical model “offers a stratigraphic view of disorder in which biology is the foundation, and psychological and social dimensions of sickness are seen as epiphenomenal, superstructural layers to be stripped away to get at the infrastructural, i.e. biological base” (p. 143-144) (129).

In the social sciences the biopsychosocial model has been more fully embraced for its efforts to forge a multilevel, multisystems approach to human functioning (128). In the field of social work the biopsychosocial perspective is considered a foundation of social work theory and practice (130). Suls and Rothman (2004) recommend that investigators need to design research “that embraces, rather than shies away from the complexity of the phenomena of interest” (p. 123) (128).

“At the present time such models can only identify factors or variables that can be demonstrated to be protective or to increase risk, but the relative variance accounted for by these various factors is largely unknown....it is not at all clear which variables account for the greatest amount of variance and which may be trivial” (p. 427) (131).

Despite the overwhelming focus on the biological-biomedical model in the epilepsy field, several scholars have embraced more of a biopsychosocial view of epilepsy. This has culminated in the recognition that poor mental health in PWE is related to: clinical factors (seizure type, seizure severity, medication side effects), biological factors (dysfunction of the central nervous system associated with a person’s epilepsy) and psychosocial factors (social and interpersonal stresses a person encounters through stigma, social isolation and unemployment) (132, 133).

In addition, the argument is strong that mental health disorders, such as depression, anxiety and bipolar disorder, do not fit within a strictly biological-biomedical definition of disease. First, mental health conditions do not have an identified specific etiology (a germ or virus). Secondly, mental health conditions are not qualitatively different from some aspects of normal functioning. Third, they do not show a demonstrable associated physical pathology or marker and lastly, they are not biological processes that continue independently of environmental conditions outside of the body (126). Overall this lack of support suggests that mental health conditions do not fit the requirements of the traditional biological-biomedical model. Rejection of the biological-biomedical model does not imply an outright rejection of the scientific method or empirical evidence instead the “evidence demands rejection of the biomedical model as the sole explanatory framework for mental disorders” (p. 30) (126). The biopsychosocial model is therefore an important concept for understanding the variables that account for

the greatest amount of variance (131) in quality of life. Psychological and social factors are particularly important and need further discussion of their importance to PWE.

Psychological

Stress

Stress has been operationalized in terms of its immediate physical symptoms; “the non-specific response of the body to any demand” (p. 15) (134) to the importance of stress as “a broad, critical variable relating the wear and tear of life to health and well-being” (p. 654) (135). Stress stimuli defined as “events impinging on a person” have been conceptualized on three levels: major changes affecting large numbers of people, major changes affecting on or a few people and daily hassles (p. 12) (134).

The stress stimuli perspective identifies the acute and chronic components of stress. Baum (1990) defines chronic stress as “demands, threats, perceived harm or loss, or responses that persist for long periods of time” (p. 662). Living with epilepsy and the unpredictable nature of seizures and their long term chronic impact on physical, mental and social health are consistent with the definition of chronic stress. This is reflected in research showing persons with uncontrolled seizures are prone to a greater sense of external locus of control (a belief that the environment, some higher power or other people controls their life) over an internal locus of control (a belief that one has control of their life) (136).

In addition, several clinical epilepsy studies found PWE report higher scores on measures of learned helplessness (137, 138), a well-established behavioral and psychological outcome that is often the result of extended periods of chronic stress (139). Learned helplessness suggests people learn to behave helplessly, even when an

opportunity is restored to avoid unpleasant or harmful circumstances. This often is the result of a perceived absence of control over the outcome of different situations (i.e., seizures).

Not surprisingly, PWE often report a connection between stress and their seizures. Tempkin and Davis (1984) found high stress levels and stressful events were associated with more frequent seizures (140). In another survey, 64% reported a belief that stress increased the frequency of their seizures (141). One cross-sectional study of seizure precipitants found almost 70% of PWE identified they had more seizures when they were tense or depressed and only 4% said they had seizures when they were happy (142). In another small cross-sectional study (n = 100) 53% of respondents identified being “tense, anxious, worried, stressed or nervous” as a seizure precipitant (143). Similar findings were confirmed in a recent cross-sectional study of 223 persons with partial epilepsy that found 67% of patients reported worry and stress as a significant trigger of their seizures (144). However, these findings contrast with larger studies.

A larger study of 400 PWE at a tertiary care epilepsy center found across eight seizure types that 30% identified stress as a precipitant of their seizures (145). A study of 1,677 PWE across three countries found 18.2% in the U.S., 24.3% in Denmark and 21.5% in Norway reported emotional stress as the most frequently reported seizure precipitant (146). These differences are likely due to sample size differences and different methodologies for assessing seizure triggers.

Furthermore, stress is strongly associated with symptoms of depression in PWE. One investigation found fear of seizures, social stigma, unemployment, discrimination, and lack of social support are stressors that contribute to depression in persons with

epilepsy (99). A recent cross-sectional study of 150 adult persons with epilepsy found stress accounted for 39% of the variance in depression scores as measured by the Beck Depression Inventory (147).

The current data do not support a potential cause and effect relationship between stress, epileptic seizures (a symptom) and epilepsy (the disease). Clinically, all persons (regardless of having epilepsy or not) have a seizure threshold. Metabolic changes in blood sugar, electrolytes or toxic levels of certain medication can lead to seizure activity in the brain. Stress, sleep deprivation, alcohol consumption and certain medications can lower this seizure threshold (148, 149). PWE, being more prone to seizures, may therefore have more sensitivity to stress.

Psychological disorders

In population based studies it is well established in the literature that PWE have a significantly higher prevalence of psychological and psychiatric comorbidity compared to the non-epilepsy population. In the CCHS 2.1, the lifetime prevalence of any mental health disorder in PWE was 35.5% (95%CI: 25.9-44.0) versus 20.7% (95%CI: 19.5-20.7) for those without epilepsy and the prevalence of any mental health disorder in the past 12 months was 23.5% (95%CI: 15.8-31.2) for PWE versus 10.9% (95%CI: 10.4-11.3) for those without epilepsy (40).

In PWE, the most prevalent mental health disorders are mood (depression and bipolar disorder) and anxiety disorders. Based on the World Mental Health Composite International Diagnostic Interview (WHMH-CIDI) the lifetime prevalence of a mood disorder for PWE (n = 253) in the CCHS 1.2 (n = 36,984) was 24.4% (95%CI: 16.0-32.8) compared to the non-epilepsy population 13.2% (95%CI: 12.7-13.7). For mood disorder

in the last 12 months, the prevalence in PWE was 14.1% (95%CI: 7.0-21.1) compared to the non-epilepsy population 5.2% (95%CI: 4.9-5.5) (40).

Depression

Gaitatzis and colleagues (2004) found an overall rate ratio of (RR = 1.98, 95%CI: 1.87-2.09) for depression in PWE compared to those without epilepsy, regardless of age or gender in the prospectively collected UK General Practice Research Database of over 1 million residents (118). Estimates of lifetime prevalence of depression in PWE range from 29% in population based studies to 50% in tertiary referral centers (150). This contrasts with lifetime prevalence rates of depression estimates in the general population of 16 to 22% (151, 152).

Furthermore, PWE with depression have significantly more medical and psychiatric visits (153), higher levels of perceived seizure severity and poorer seizure recovery than those without depression (154). This is consistent with general population research from the Canadian Community Health Survey: Mental Health and Well-Being (CCHS 1.2) study which found depression was associated with frequent psychiatric and somatic comorbidity, high levels of disability and health service use (155).

Several studies have suggested a bi-directional relationship between depression and seizure frequency (156, 157). Persons with a history of mood disorders have a four to seven fold risk of developing epilepsy (100, 158, 159). In a case-cohort study of elderly persons with epilepsy diagnosed between 1955 and 1984 in residents of Rochester, Minnesota, major depressive disorder was associated with an eightfold risk for developing the partial onset seizures and a twofold risk for developing generalized-onset seizures. This risk remained even after controlling for age, sex, length of medical follow-

up and medical therapies for depression (158). Based on a population case-control study of all newly diagnosed unprovoked seizures among Icelandic children and adults aged 10 years and older, major depression was a risk factor for developing an unprovoked seizure regardless of DSM-IV diagnosis (159).

The most recent evidence for bi-directionality comes from a Swedish case-control study that assessed the risk of developing unprovoked epileptic seizures before and after hospitalization for a psychiatric diagnosis (157). The age-adjusted Odds Ratios (95% confidence interval) for unprovoked seizures was OR = 2.5 (95%CI: 1.7–3.7) after a hospital discharge diagnosis for depression, OR = 2.7 (95%CI: 1.4–5.3) for bipolar disorder, OR = 2.3 (95%CI: 1.5–3.5) for psychosis, OR = 2.7 (95%CI: 1.6–4.8) for anxiety disorders and OR = 2.6 (95%CI: 1.7–4.1) for suicide attempts.

Bipolar disorder

PWE are also significantly more likely to report other mood disorders such as bipolar disease. The prevalence of bipolar disorder in PWE is estimated between 3% and 8% (160). This contrasts with bipolar I and bipolar II lifetime prevalence rates in the general population ranging of 0.4 to 1.6% and estimated lifetime prevalence rates of bipolar spectrum disorders that range from 2.8 to 6.5% (161). In a large survey of the U.S. population (n = 85,358) bipolar symptoms were reported in 12.2% of persons with epilepsy compared to persons with other chronic conditions such as migraines (7.2%), asthma (5.9%), diabetes (3.2%) and a control group of persons without any of these conditions (1.7%) (162). In smaller clinic based studies, 14.5% of persons with epilepsy report manic/hypomanic symptoms (163). PWE and manic/hypomanic symptoms reported worse quality of life than those without manic/hypomanic symptoms (163).

Anxiety

Anxiety is also a common psychological comorbidity in PWE. Gaitatzis and colleagues (2004) found an overall rate ratio of (RR = 1.99, 95%CI: 1.85-2.14) for anxiety in PWE compared to those without epilepsy, regardless of age or gender (118). A Dutch study comparing rates of anxiety in PWE at a tertiary center to the general population found PWE reported lifetime anxiety of 30% versus 19% in the general population, while anxiety in the last year was 25% for PWE versus 12% in the general population (164). In the CCHS 1.2, the prevalence of lifetime anxiety disorder in PWE was 22.8% (95%CI: 14.8-30.9) compared to 11.2% (95%CI: 10.8-11.7) and anxiety disorder in the past 12 months the rate was 12.8% (95%CI: 6.0-19.7) for PWE and 4.6% (95%CI: 4.3-4.9) in the non-epilepsy population (40). In specialist settings the prevalence of anxiety in PWE is thought to exceed 50% (165, 166).

Mental health and quality of life

Numerous studies have found psychosocial factors and poor mental health, rather than clinical variables (i.e., age of onset, seizure frequency and side effects of AEDs) have the greatest impact on quality of life in epilepsy (2). So far these findings are strongly correlational and therefore cannot establish cause and effect.

Gilliam found the severity of depression (based on the Beck Depression Inventory) was highly correlated with health-related quality of life ($r = -0.49$, $p < 0.0001$) but not with seizure frequency ($r = 0.01$, $p = 0.93$) (3). Perrine (1995) found the mood dimension of the QOLIE explained 46% of the variance in overall epilepsy-specific quality of life in multivariate regression analyses (1). More recent data from Boylan and colleagues (2004) found Beck Depression Inventory scores in persons with treatment

resistant epilepsy (defined as seizure frequency greater than 1 per year despite therapy) explained significantly more of the variance in quality of life scores ($R^2 = 0.51$) compared to number of seizure per year ($R^2 = 0.02$) (4).

Mental health services for persons with epilepsy

Despite extensive population and clinical research establishing the impact of poor mental health on PWE, previous studies found 38% of patients with major depressive disorder were never referred for treatment and 68% of those with minor depression were untreated (7). Another study found that only 35% of 60 patients with symptomatic depression for >1 year were offered treatment within the first 6 months of symptom onset (8). Furthermore, Gilliam et al. found that 82% of neurologists in their survey do not routinely screen PWE for depression (167). A more recent survey of epileptologists found 62% of respondents do not routinely screen for depression and 42% did not feel comfortable initiating treatment for depression (11).

Previous research found many PWE view their main handicaps as psychological (rather than purely physical) and complain about a lack of counseling and support (5). Population research from the Canadian CCHS 1.1 found 38% of depressed PWE had no consultations with a mental health professional in the past year (42) despite universal insurance coverage for mental health services in Canada. This contrasts with an examination of mental health services for emotional symptoms in the past year and barriers to treatment in the CCHS 1.1. The prevalence of 12-month help seeking for emotional symptoms was 8.3% (99%CI: 8.1-8.6) and 0.6% (99%CI: 0.49-0.62) for those who perceived a need for treatment without seeking help (168). In a recent study examining variables associated with utilization of healthcare resources in PWE (n = 256)

found scores (QOLIE-10) and seizure frequency were independently associated with the number of emergency room visits (169).

The rapid increase in effective disease-specific medical interventions has reinforced the health care system's move towards sub-specialization and compartmentalization of medical care (170). Furthermore, Richter argues the chronically mentally ill, not only lack integration into the social system, but also an incomplete integration into the health care system (121). The contemporary health care system he argues is fragmented and disintegrated. This is demonstrated in how the professional competencies are divided by tradition as well in the poor connection between the ambulatory sector, the hospital sector and complementary services (121).

This fragmentation and disintegration is reflected in the absence of epilepsy in a 1995 health psychology text by Nicassio and Smith (1995) titled *Managing Chronic Illness: A Biopsychosocial Approach* (171). Sperry's 2006 book *Psychological Treatment of Chronic Illness: The Biopsychosocial Therapy Approach* on the other hand does include a lengthy discussion of epilepsy in the chapter "Biopsychosocial Aspects of Some Chronic Illnesses" (44).

The recognition of the importance of integrating psychological and social components into the wider health care system goes back to a seminal 1974 Canadian report. In *A New Perspective on the Health of Canadians*, LaLonde (1974) identified the need to understand the quality, quantity and distribution of health services in the community (172). LaLonde's *Health Field Concept* highlighted "the greatest potential for defeating illness, facilitating health and promoting life would come from intervention

programs that focus on the psychology and sociology of illness, rather than on the biology” (p. 51) (126).

The importance of mental health services is reflected in recent publications that include psychological therapy as part of the biopsychosocial model (44). Suggested methods range from patient education, self-management to specific therapeutic methods such as cognitive behavioral therapy. Furthermore, social workers and psychologists are an integral part of the health care system. Both fields have specializations in health (hospital social work and health psychology). These are reflected in professional journals such as *Health & Social Work* and *Health Psychology*. Social work in particular embraces a theoretical approach that recognizes the environmental influence on the individual (i.e., human behavior in the social environment) and that social services are part of the biopsychosocial model (173, 174). The limitations of all therapeutic interventions however need to be recognized:

“Although drugs do not operate independently from the patient’s expectations, beliefs and motivation, stimulations of the mental state by the biological treatment cannot be rejected by the patient. Psychotherapeutic interventions are far more ambitious, they require patient’s acceptance for a successful outcome” (p. 27) (121).

Due to the chronic nature of mental illness many of these individuals cannot be treated via psychopharmacology alone (121). Everyday functioning and social functioning cannot be seen as really belonging to psychiatry’s domain: “Psychiatry as a medical subdiscipline is not able to provide adequate social support patients need. Nor is psychiatry able to provide patients with necessary coping skills” (p. 28) (121).

The recent 2012 IOM epilepsy report also acknowledged the importance of mental health services for PWE:

“Mental health services are a critical component of comprehensive and effective epilepsy care for many people. A range of health professionals including psychiatrists, neurologists, primary care physicians, psychologists and counselors, psychiatric nurses, and clinical social workers can provide the necessary services” (p. 167) (18).

While the literature review would suggest a significant amount of psychosocial interventional research on epilepsy this is not the case. A literature review in social work abstracts (1964-2011), using the term "epilepsy" revealed only 49 articles. In a search of sociological abstracts (1963–2005) there were only 58 publications. Most of these were published in the late 1970s. A Medline search through PubMed (1945-2012) using "epilepsy and social work" identified only 296 articles. In order to broaden the search, the terms “epilepsy and psychotherapy” were used in a PsychINFO (1967-2012) search this search yielded 289 hits.

Psychology

Presently there are no evidence based practice guidelines for psychological therapy in persons with epilepsy. Of the existing studies of psychotherapy, the most frequently studied approach has been Cognitive Behavioral Therapy (CBT). Despite numerous published articles, all previous investigations have involved very small sample sizes ($n < 30$) (175-178). A recent review of psychotherapy studies for PWE by the Cochrane Collaboration concluded "In view of methodological deficiencies and limited number of individuals studied, we have found no reliable evidence to support the use of these treatments and further trials are needed" (p. 1) (179).

Social Work

Social services provided to PWE by social workers include patient education, preventive counseling, case management, individual counseling, group counseling,

family counseling and community education (180). Early papers in the field focused on the importance of psycho-education in helping patients (especially those with childhood onset) and their families accept the epilepsy diagnosis (181). This literature concentrates on educating social work practitioners about common psychosocial issues for PWE such as low self-esteem, lack of socialization, familial fear and guilt, dependence, anger and lack of control, societal discrimination and psychological mechanisms (182-186).

Previous papers also promoted an interdisciplinary treatment approach for epilepsy (182) as well as the importance of advocacy for battling discrimination in school and work settings (183). One early paper in the field of medical social work mentioned the importance of PWE needing courage and hope (187). However the social work literature has also taken a deficit position to epilepsy:

"However, individual case work with these individuals is frequently frustrating because resistance to relinquishing the sick role proves overwhelming. In terms of change the ambivalence of the desire to change can be strong in PWE because they have much to lose by relinquishing the one role they have felt secure" (p. 23) (188).

Other aspects of the social work literature have focused on the presentation of particularly successful case studies (189) or of small cases series (190). Group therapy approaches were the main interventional approach (182, 188). Group work in epilepsy has identified a successful model that focused on: identity, exploration of goals, modifying behavioral patterns and assessment of progress (188). The group therapy literature also mentioned the importance of building strengths (a sense of independence, a place to try out new behaviors, social support and the prevention of dependence) and utilizing the group setting to promote individual change (182).

Social

Problems of living associated with epilepsy have long been a concern in the epilepsy field (68). Many of the psychological and environmental stressors found on Axis IV of the DSM-IV match what has been reported in the epilepsy literature. These include problems with primary support groups, problems related to the social environment, educational problems, occupational problems, housing problems, economic problems and problems with access to health care services (191).

Human capital (education, employment, income)

Previous investigations found the incidence (192) and prevalence of epilepsy in adults (38, 193, 194) increases with socioeconomic deprivation. Population studies from the United States show persons with a history of epilepsy report lower educational attainment and lower household income compared to those without epilepsy (19, 195, 196).

PWE are known to have significant difficulties obtaining and maintaining employment (197). Human capital factors improve health both directly and indirectly through work and economic conditions, psychosocial resources and a healthy lifestyle (198). Limited education and employment impact healthcare access, as well as environmental and lifestyle risk factors, for PWE and place them at greater risk for poverty. Therefore quality of life trajectory in epilepsy is modified by higher education and occupational attainment (199). The field of social work in particular has long embraced this “social determinants of health” perspective (200).

A recent survey of epileptologists, neurologists and professionals in epilepsy care found a lack of awareness about social services as the most commonly identified

management barrier to optimal epilepsy care (201). The three greatest healthcare system barriers to positive patient outcomes identified in the survey were: lack of public awareness of epilepsy, availability of social services and the cost of anti-epileptic drugs (201). The authors concluded that persons with epilepsy need better social support systems to address health insurance needs and remove economic barriers to care. It was also concluded that while physicians were aware of the economic barriers to medication, they are more focused on seizure control than financial matters. A recently published epidemiological study found PWE living in poverty were half as likely ($OR = 0.5$, 95%CI: 0.3-0.9) to report taking medication for their seizures once material factors (annual income and living situation) and healthcare access were controlled for (202).

Marital status

It has been suggested that the persons most debilitated by epilepsy are not those with the highest seizures rates but rather those who lack social support (203) defined as “the commitment, caring advice and aid provided in personal relationships” (204). Previous population studies have found PWE are significantly less likely to report being married compared to those without epilepsy (196, 205).

Longitudinal data (mean follow up of 34 years) from Norway found having epilepsy at school age has a significant negative impact on education and marital status later in life (206). In a thirty year longitudinal study from Finland, childhood onset seizures were found to have long-term adverse impact on education, employment, marriage and having children (207). This negative impact was still present even when persons were seizure free without medication for many years (207, 208).

Marriage, as a specific source of social support, may increase one's ability to cope, either because of coping assistance or because marriage enhances one's own coping capacity (209). Previous studies also suggest that married persons report better psychological and physical health compared to those who are not married (210). Therefore, social support from marriage may be particularly important as PWE are more likely to suffer from poor mental health (150, 211). Married people consistently report higher levels of life satisfaction than unmarried people (212, 213).

Marriage, is thought to increase one's ability to cope, either because of coping assistance or because marriage enhances one's own coping capacity (209). Intimate relationships are also thought to influence health outcomes indirectly through their positive effect on mood (209, 214). In one recent study, PWE with poor affectionate support (a type of support that can come from marriage) were significantly more likely (OR = 9.1, 95%CI: 6.2–13.3) to report fair/poor self-rated health status (215).

Stigma

Stigma has been conceptualized by Goffman as an "an undesired differentness" and an attribute that is deeply discrediting (216). He went on to say the stigmatized person is seen by others as "not quite human" and therefore the target of discrimination. Goffman believed that although a stigmatized person can attempt to rid themselves of the contaminated social identity, they can never acquire the status of normal; just one who was formerly contaminated. Stigma therefore leads to a social identity that is permanently flawed. Studies of PWE support this long term impact of stigma even when seizures have remitted (217).

The process of concealing epilepsy is not always voluntary. Stigma in epilepsy is thought to be the result of information management (what to disclose about their condition and to whom). This leads to planning in order to avoid high-risk situations that could lead to disclosure which contribute to feelings of stigma (218). PWE and their families suffer from stigma that may impact how they are perceived and view themselves (219). This may be worse when the diagnosis occurs early in life (220). "Epilepsy is not just a clinical disorder but a social label" (p. 171) (221). Persons with epilepsy (PWE) not only have to cope with the complex demand of a chronic illness, but also have to deal with health-related stigma and prejudice in employment and education settings.

One epilepsy study found patients who develop healthy attitudes were active and flexible, focusing on possibilities and planning how to handle negative emotions. In contrast the "handicapped" group was passive and resigned to epilepsy in a negative way. They were fearful of being exposed and tended to focus on obstacles and their negative emotions (222). Other investigators have also recognized that feelings of stigma due to epilepsy are not inevitable: "Some individuals appear to have an immunity to stigmatizing forces and misconceptions, where as others are vulnerable" (p. 165) (223). One area where stigma may manifest itself is in a person's evaluation of their connection to the community.

Sense of belonging to the community

Sense of belonging has been defined "as the experience of personal involvement in a system or environment so that persons feel themselves to be an integral part of that system or environment" (p. 173) (224). Previous research suggests that the psychological sense of community "is an experience, generated within the interplay of individual and

group, which engenders the perception of belonging and ameliorates feelings of isolation” (p. 195) (225). Psychologically, a sense of community is thought to have a beneficial effect on stress, decrease loneliness and engendering feelings of hope through the importance of affiliations with others (225).

Sense of belonging to the community is conceptually similar to a "sense of community" which has been used to characterize the relationship between the individual and the social structure (226). Sense of community has been defined previously by feelings of bondedness, extent of residential roots, use of local facilities and degree of social interaction with neighbors (227). McMillian and Chavis (1986) sought to expand this definition by focusing on four elements; membership (feelings of belonging or of sharing a sense of personal relatedness), influence (a sense of mattering, of making a difference to a group), integration and fulfillment of needs (member needs will be met by the resources received by being a member of the group) and shared emotional connection (commitment and belief that members have shared and will share history, common places, time together and similar experiences) (p. 9) (227).

General population research supports an association between community level social connection and self-rated health status (228). Socially isolated people are more likely to rate their health status as poor (229). Persons in poor environments experience significantly higher amounts of stress, poor mental health (230, 231) and are more likely to adopt unhealthy coping behaviors such as smoking (232) which can lead to other comorbid conditions (i.e., heart disease, cancer and stroke).

A strong sense of belonging to the community is thought to be the result of strong social networks which in turn broaden feelings of solidarity (233). The 2003 General

Social Survey (GSS) on Social Engagement of over 25,000 Canadians found 19% reported a very strong sense of belonging to the community, 49% somewhat strong and 30% somewhat weak or very weak (234). Sense of belonging to the community was also positively correlated with household income and age, but negatively correlated with size of the community but no differences by educational attainment (234). In the 2002 CCHS 1.2, participants reporting their sense of belonging to their community as strong/somewhat strong had lower rates of depression in the past 12 months (OR = 0.81, 95%CI: 0.69-0.96) (235) however the analysis did not control for any biological-biomedical, psychological or social factors.

An examination of the relationship between sense of belonging to the community and self-rated health status (dichotomized as very good or excellent versus poor, fair or good) found a very strong sense of belonging to the community was significantly associated with "very good or excellent" self-rated health status (OR = 1.7, 95%CI: 1.6-1.9) and "somewhat strong" sense of belonging to the community (OR = 1.3, 95%CI: 1.2-1.4), but not with ratings of "somewhat weak" (OR = 1.0, 95%CI: 1.0-1.1) or "very weak" sense of belonging to the community (reference group = 1) (236). In the 2002 CCHS 1.2 survey investigators found that persons with a stronger sense of belonging to the community and higher social support reported lower rates of depression (235).

A previous study examining the relationship between sense of belonging to the community and health found the magnitude of the odds ratio for belonging to the community was not substantially affected; suggesting sense of belonging to the community is conceptually different from social support and has an independent relationship with self-rated health status (236). Indicators of social isolation such as

living alone or having no family are often subsumed to be indicative of emotional isolation, loneliness or poor health (237). A random sample of people over the age of sixty in Manitoba (n = 743) found quantitative measures (no daily contact and minimally weekly contact), no children, having no children and being unmarried or having no children plus living alone were not related to measures of life satisfaction (237).

Overall, the literature supports a need to understand quality of life in PWE from a broader lens than the biological-biomedical approach that currently dominates clinical care. Despite the continued focus on seizures and biomedical treatment, extensive literature over the years have found that psychological and social factors contribute significantly to quality life.

The biopsychosocial model provides a strong rationale for a multidimensional model that incorporates psychological and social factors into the understanding of chronic diseases like epilepsy. In the research that was undertaken I aimed to broaden the understanding of quality of life in PWE by using the biopsychosocial model. The research suggested potential moderating effects of the biopsychosocial model on quality of life. Furthermore, this study was an important step in understanding quality of life in epilepsy and the potential moderating effect of mental health services from a population perspective.

Moderation versus Mediation

Baron and Kenny (1986) define a *moderator* as “a qualitative (e.g., sex, race, class) or quantitative (e.g., level of reward) variable that affects the direction and/or strength of the relation between an independent or predictor variable and a dependent or criterion variable” (p. 1174) (238). Within the framework for correlational analysis, they

describe a moderator “as a third variable that affects the zero-order correlation between two other variables”. In testing moderation, the causal relation between two variables changes as a function of the moderator variable therefore statistical analyses must measure and test the differential effect of the independent variable on the dependent variable as a function of the moderator (238).

Moderators help specify when certain effects will hold “under what conditions” (239). Moderating variables: “always function as independent variables, whereas mediating events shift roles from effects to causes depending on the focus of the analysis” (p. 1174) (238). Tests for moderation are focused on measuring and testing the differential effect of the independent variable on the dependent variable as a function of the moderator. A variable functions as a *mediator* to the extent that it accounts for the relation between the independent variable (predictor) and the dependent variable (criterion). Mediators then get at “how and why” effects occur (239).

Two criteria help establish whether any variable functions as a moderator or mediator: eligibility and analytic criteria (239). Eligibility is based on temporal precedence and association, as the ultimate goal of moderation and mediation are to detect causal chains among variables that lead to the outcome. Analytic criteria refer to the statistical methods used to demonstrate whether variable functions as a moderator or a mediator (239).

Critical to testing for mediated effects is the prerequisite that there be a significant association between the independent variable and the dependent variable before testing for a mediated effect (240). Examples are the linear model and structural equation modeling (SEM) (240). Regression models are preferred for testing moderation effects,

as where SEM may be more preferable for mediating effects (240). Regression analyses often include an interaction term (the product of the two main effects) to achieve this as where SEM examines model fit and helps control for measurement error. As the Baron and Kenny approach discussed it is unlikely the effect of one variable (A on C) be reduced from significance to zero in psychological research. Therefore the degree to which the effect is reduced (for example the change in regression coefficients) indicated the potency of the mediator (238).

The approach of Barron and Kenny is consistent with the more traditional use of hypothesis testing. Kenny reflected recently stated that their classic paper “*The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations*” was too formulaic in that it implied that if a series of regression analyses are estimated the researcher has a definite answer about mediation (241).

Since Barron and Kenny’s paper there has been more movement towards use of effect sizes as popularized by Jacob Cohen (239). Other limitations to the Baron and Kenny approach include not specifying criteria for temporal precedence for determining moderation. The more recent MacArthur approach has been more specific with this regard: “a moderator must always precede and not be associated with that which it moderates, and a mediator must always follow and be associated with that which it mediates” (p. S106) (239). Kenny however argues that randomized experiments are not the only legitimate design for drawing causal conclusions as the requirement of manipulation is not ethically or practically possible especially in the case of psychological processes that can only be measured and not manipulated (241).

For this research Cohen's set correlation procedure allows for the testing of the individual biological, psychological and social components of the model as well as the use of multiple dependent variables. Set correlation also provides, via standardized beta weights and partialling (a procedure that controls for the independent variables in each domain), a greater understanding of quality of life domains and the variables that best explain them in PWE via a more exploratory approach.

Since the CCHS is cross-sectional, the determination of a causal process is not feasible. However in the process of conducting the statistical analysis, potential moderating effects via the biopsychosocial model may be suggested. I put forth the following hypotheses to test those empirically supported in the literature:

Research Hypotheses

Research question 1. Is quality of life in PWE better explained by the biopsychosocial model than the biological-biomedical model?

Hypothesis 1.1. The individual domains (biological-biomedical, psychological and social) are all independently associated with quality of life.

Hypothesis 1.2. The full model that includes the biological-biomedical, psychological and social domains will explain quality of life in persons with epilepsy better than the biological-biomedical model alone.

Hypothesis 1.3. Individually, the psychological and social domains will explain quality of life better than biological-biomedical model.

Research question 2. Does use of mental health services (social workers/counselors and psychologists) have a moderating effect on quality of life in PWE?

Hypothesis 2.1. Use of mental health services (social workers/counselors and psychologists) will explain additional variance in quality of life for PWE.

Chapter III: Methods

To answer these questions I used secondary data from the Canadian Community Health Survey (CCHS). The CCHS is a cross-sectional survey that collects information related to health status, health care utilization and health determinants for the Canadian population. Populations excluded from the sampling frame include individuals living on Indian Reserves, the Crown Lands, institutionalized residents, full-time members of the Canadian Forces and residents of certain remote regions. Despite these excluded populations, the CCHS covers approximately 98% of the Canadian population.

The primary use of the CCHS data is for health surveillance and population health research based on a wide range of topics including demographic characteristics, socioeconomic profiles, psychological health, physical activity, body mass index (BMI), smoking, alcohol consumption, general health, chronic health conditions and use of health care services. The CCHS is a periodic survey design where similar measurements are made on samples from an equivalent population (same geographical boundaries, age limits) at different points in time (242). In this design elements of the survey may or may not be included in more than one round of data collection. This provides a series of cross-sectional estimates which can be used to provide estimates of population parameters at distinct points in time or during periods of time where changes are treated as negligible. Since new samples are gathered over the survey waves, pooled estimates are an average

across the period of time. This methodology is however not able to measure components of individual change.

Three waves of the survey data were obtained from Statistics Canada: CCHS 2001 (CCHS 1.1), 2003 (CCHS 2.1) and 2005 (CCHS 3.1) through an annual microdata file. The response rate was 85% for the CCHS 2.1 (38) and 79% for the CCHS 3.1 (243). Statistics Canada has a methodology for combining the CCHS collection years for the examination of rare populations (244) such as epilepsy. I combined the 2003 (CCHS 2.1) and 2005 (CCHS 3.1) waves for this study, since these two waves have the most complete data elements to answer the proposed research questions.

Participants/sampling

The CCHS data are based on interviews with more than 130,000 respondents aged 12 or older residing in households in all provinces and territories. For administrative purposes, the CCHS divides the 13 provinces in the country (Newfoundland, Prince Edward Island, Nova Scotia, New Brunswick, Quebec, Ontario, Manitoba, Saskatchewan, Alberta, British Columbia, Yukon, Northern Territories and Nunavut) into 136 health regions where each territory is designated a single health region (245). Provinces with larger populations are broken down into a number of health regions. A multi-stage sample allocation strategy gives relatively equal importance to the health regions and to the provinces.

The CCHS used three sampling frames to select the sample of households: 49% of the sampled households come from an area frame (a list of geographic regions based on the Labor Force Survey), 50% comes from a list frame of telephone numbers and the remaining 1% comes from a Random Digit Dialing (RDD) telephone number frame. For

the majority of health regions, 50% of the sample is selected from the area frame and 50% from the list frame of telephone numbers.

A multistage stratified cluster design was used in the CCHS to sample dwellings within the area frame. In the first stage of the design, a list of the dwellings was created. At the second stage, a sample of dwellings was selected from this list. The households in the selected dwellings formed the sample of households. A majority (88%) of the targeted sample was selected from the area frame (245). The sample size was enlarged during the selection process to account for non-responses and units outside the coverage (vacant homes, institutions or non-working telephone numbers).

A list frame of telephone numbers was used to complement the area frame. As part of this procedure, the Canada phone directory (a commercially available CD-ROM consisting of names, addresses and phone numbers) was linked via administrative conversion files. This procedure was used to obtain postal codes which were then mapped to the Health Regions to create the list frame strata (one per Health Region). A simple random sampling process was used to select the required number of telephone numbers in each stratum. A hit rate between 70% to 80% was observed using the list frame approach (246). For the Random Digit Dial (RDD) frame, additional telephone numbers were selected to account for the numbers not in service or out-of-scope.

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.

Data collection procedures

Data were collected directly from survey respondents via questions designed for computer-assisted interviewing (CAI). As part of the questionnaire development process, an associated logical flow into and out of the questions was programmed. This includes specifying the type of answer required, minimum and maximum values and procedures for handling non-response items. The CAI system allows for immediate feedback to the respondent and the interviewer in order to avoid or correct any inconsistencies. As part of the CAI procedure the question text, including reference periods and pronouns, are automatically customized based on the respondent's age and gender. The CAI method determined which questions were not applicable so they could automatically be skipped.

As an ongoing survey the CCHS has three content components: the common content, the optional content and the rapid response content. The common content was collected from all survey respondents. Some modules are collected every year and remain relatively unchanged over several waves of the study. Other common modules are collected for one or two years and rotate every two or four years. New questionnaire modules and revisions to existing CCHS survey content are tested using cognitive interviews and focus groups to ensure that questions and concepts are appropriately worded. Field testing is often used to test new modules or significant revisions of the collection instrument.

In cases where the selected respondent was incapable of completing an interview (i.e. due to physical or mental health impairments) another knowledgeable member of the household supplied information about the respondent (a proxy interview). Proxy interviewees were able to provide accurate answers to most of the survey questions,

however the CCHS designers believed the more sensitive or personal questions were beyond the scope of knowledge that could be provided by a proxy respondent. This resulted in more unanswered questions. Therefore, every effort was taken by the CCHS staff to keep proxy interviews to a minimum.

Interviewers started off the survey with the statement: “This survey deals with various aspects of your health. I’ll be asking about such things as physical activity, social relationships and health status. By health, we mean not only the absence of disease or injury but also physical, mental and social well-being.” This introduction is consistent with the WHO definition of health and also provides a supports for the biopsychosocial perspective that is the focus of this research as well as LaLonde’s (1974) *Health Field Concept* a Canadian public health report which called for a focus on “the psychology and sociology of illness, rather than on the biology” (p. 51) (126).

Epilepsy case definition

The diagnosis of epilepsy was assessed in the CCHS as part of a list of twenty-seven chronic medical conditions. Respondents were asked specifically “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 a list of several conditions respondents were asked “Do you have epilepsy?” This dichotomous outcome has been used in previous epidemiological surveys.

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% (247). This is comparable to 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 (248).

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 (38). This case definition has been used in the Canadian National Population Survey and the Canadian Community Health Survey and yielded point prevalence estimates of 5.2 per 1,000 and 5.6 per 1,000 which are both consistent with the rate of active epilepsy 6 per 1,000 found in other epidemiological surveys using various case definitions and ascertainment methods (249, 250). For example, the 1990 Ontario Health Survey reported a point prevalence rate of 5.8 per 1,000 using the question “Do you have epilepsy” for case ascertainment (251).

Independent variables

Comorbid somatic conditions

Comorbid somatic conditions were also assessed in the CCHS as part of a list of twenty-seven chronic medical conditions. Respondents were asked specifically “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”. The comorbid conditions of interest include asthma, diabetes, arthritis, hypertension, heart disease and stroke.

Self-reported chronic diseases reflect medical dimensions of health which can be objectively verified by an external observer based on physical examination, laboratory tests and/or medical records (72). A study examining data from the National Health and Nutrition Examination Survey and the 2003 wave of the Health Survey for England found self reported health measures of diabetes, hypertension, heart disease, myocardial infarction, stroke, chronic lung diseases, and cancer based on the question “Did a doctor ever tell you that you had. . . ?” were almost identical to biological measures such as physical and laboratory examinations that were captured as part of the surveys (252).

Mood disorders and anxiety disorders

The two areas of interest in this study were broadly defined as mood disorders and anxiety disorders. These mental health diagnoses were dichotomized based on the questions “Do you have a mood disorder such as depression, bipolar disorder, mania or dysthymia” and “Do you have an anxiety disorder such as a phobia, obsessive-compulsive disorder or a panic disorder?”

Self-perceived life stress

To assess self-perceived life stress I used a 5 point Likert scale assessment based on the question “Thinking about the amount of stress in your life, would you say that most days are not at all stressful, not very stressful, a bit stressful, quite a bit stressful or extremely stressful?” In the CCHS, this is considered a general assessment of day-to-day stress levels (253, 254). Limitations of epidemiological research often necessitate the use of a one or two questions to assess a complex phenomenon such as stress (255). A examination of the reliability of two similar single-item measures of stress found good test-retest reliability (kappa and intraclass correlations between 0.66 and 0.74) (255).

Health care utilization

The CCHS included an assessment of health and mental health care utilization (number of visits in the past year) by healthcare professional type. In terms of primary care services the CCHS asked: “In the past 12 months, how many times have you seen, or talked on the telephone, about your physical, emotional or mental health with a family doctor (pediatrician) or general practitioner?”

The CCHS also asked specifically about the use of mental health providers as part of their optional modules through the questions: “In the past 12 months, how many times have you seen, or talked on the telephone, about your physical, emotional or mental health with a social worker or counsellor?” and “In the past 12 months, how many times have you seen, or talked on the telephone, about your physical, emotional or mental health with a psychologist?”

Sense of belonging to the community

Connection to the community was assessed using the question “How would you describe your sense of belonging to your local community?” Respondents were given the following choices: “Would you say it is: very strong, somewhat strong, somewhat weak or very weak?” This measure is different than traditional measures of social ties in population research such as counts of friends or perceived social support (236). I used this as a proxy measure of social isolation for PWE known as stigma.

Dependent variables

Self-rated health status

Self-rated health status, based on a five point Likert scale, was utilized as the first quality of life outcome. Self-rated health status was assessed through the question “In general, would you say your health is excellent, very good, good, fair or poor?” Self-rated health captures the subjective experience of acute and chronic, fatal and nonfatal disease; feelings of malaise and fatigue; and pain such as muscle pain, backaches and headaches (231). This question has been included in many population surveys. Retest reliability of this assessment was assessed using a weighted kappa statistic and yielded a 0.75 (95%CI: 0.71, 0.79) correlation (256). Across twenty-three studies self-rated health status (which takes seconds to obtain) reliably predicts survival in populations even when known health risk factors have been controlled for (75).

Self-rated mental health status

Self-perceived mental health status was used as the second outcome. Self-perceived mental health status was assessed in the CCHS using on a five point Likert scale based on the question “In general, would you say your mental health is: excellent, very good, good, fair, or poor?”

The Medical Expenditure Panel Survey of health care utilization and expenditures found self-rated mental health status was moderately correlated with other established multi-item measures of mental health such as the Kessler 6 (0.49), Patient Health Questionnaire-2 (0.45), Mental Component Summary (-0.47) and multiple subscales of the Short-Form 12 (range -0.33 to -0.47). Correlational analyses also found self-rated mental health and self-rated health status were moderately correlated ($r = 0.536$). In a

factor analysis study self-rated mental health loaded more onto the mental health domain 0.441 compared to the physical health domain 0.238. Regression analyses found self-rated mental health was more strongly associated with emotional role limitations than with physical limitations on the Short Form-36 (SF-36) which provides evidence of discriminant validity (79).

Life satisfaction

The last quality of life outcome of interest was life satisfaction. In the CCHS the question “How satisfied are you with your life in general?” was used to assess participants overall life satisfaction. Respondents were given the following choices “very satisfied, satisfied, neither satisfied nor dissatisfied, dissatisfied or very dissatisfied” Many previous studies have used single items such as “How do you feel about life as a whole?”, “How satisfied are you with the meaning and purpose of your life?” or “All things considered, how satisfied are you with your life?” (257-260).

Despite the development of multi-item scales, the use of a single item measures of life satisfaction such as the one used in the CCHS have remained (85). These single item global reports have good internal consistency, moderate stability and are sensitive to changing life circumstances (261). Single item global measures of life satisfaction have good convergence with informant or spousal reports and are predictive of suicide and depression (261). Discriminant validity studies have demonstrated that life satisfaction as a “global evaluation by the person of his or her life” is distinct from other influential factors such as positive and negative affect, optimism and self-esteem (84).

Data analysis

In order to represent the Canadian population in each province and territory, probability weights provided by Statistics Canada were incorporated to account for sampling probabilities and non-response. These weights provide more precise estimates of variance around point estimates however CIs may still be underestimated. Bootstrap weights used by Statistics Canada to estimate standard errors are not available in the CCHS data for public use microfile (PUMF) (243). The bootstrap weights used to account for the survey design effect are only available via secure computing facilities approved by Statistics Canada.

To overcome this limitation, an approximate method had been used in a previous investigation (262) that utilized the survey design effect into the calculation of the 95%CI estimates for all statistical routines applied in the study. This was accomplished by taking the square root of the average survey design effect. For the 2003 CCHS 2.1 the average survey design effect for all the Provinces was listed in Approximate Sampling Variability Tables in Appendix E as 2.77 (p. 1) (263). For the 2005 CCHS 3.1 the average survey design effect for all the Provinces was listed in Approximate Sampling Variability Tables in Appendix E as 2.51 (p. 1) (264). Standardized variables (z-scores) used in the 95%CIs were then re-scaled by the survey design effect. For the 2003 CCHS 2.1 this was calculated by the formula: $(z = 1.96 * \sqrt{2.77} = 3.26)$. For the 2005 CCHS 2.1 this was calculated by the formula: $(z = 1.96 * \sqrt{2.51} = 3.10)$. In order to streamline these calculations in STATA the CIs were set to 0.998 which was equivalent to both z-scores.

To examine the biopsychosocial model in epilepsy (a low prevalence condition) I combined data from the 2003 CCHS 2.1 wave ($n = 134,072$) and the 2005 CCHS 3.1 wave ($n = 132,221$). Preliminary review of the data dictionary reveals samples of ($n = 835$) PWE in the CCHS 2.1 and ($n = 867$) PWE in the CCHS 3.1. The combining of data helps protect respondent confidentiality as Statistics Canada does not allow for the release of information on subsets of data where $n < 10$ (265).

Consistent with previous investigations, I ensured that there were no clinically significant 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 (266). This pooled approach of combining the sample data at the micro-data resulted in a dataset that was treated as one sample of the population that covers the time period of the two cycles (2003-2005) (244). This method has been used in several previous investigations (267, 268). The total weighted population via the pooled approach would represent roughly twice the Canadian population. Since the goal of the current study was not to estimate the number of PWE in the population, no adjustment of the estimates (dividing estimates by 2) was needed. Hence, adjustment of percentages and regression analyses (i.e., set correlation) were not necessary (268).

Data processing

Importing of the CCHS data from the PUMF data discs was completed by the use of pre-written SPSS syntax (IBM, Chicago, IL). After importing the two data sets (2.1 and 3.1) into SPSS, the relevant variables of interest existing in both data sets were identified. An Excel worksheet (Microsoft Corp, 2003) was used to organize and

conceptually arrange the identified variables into three domains (biological-biomedical, psychological and social).

The SPSS databases were then paired down to contain only the relevant variables needed for the analyses. As part of this process geographic variables and the sample weight variable were retained. A dichotomous variable was created to indicate the wave of data. Since the CCHS dataset contains population-based data, separate datasets containing only the epilepsy cases were created using the select cases function in SPSS. The individual datasets of only epilepsy cases were then combined using a merge function in SPSS.

Since SPSS did not provide 95% CIs as part of its weighting procedures, the data were then exported into a STATA file format (STATA Corp LP, College Station, TX). STATA was utilized for the descriptive demographic analysis using the survey design effect as described above. EQS version 6.1 (Multivariate Software, Encino, CA) was used to run preliminary SEM analyses. SYSTAT version 12 (Systat Software, Inc., Chicago, IL) was used for set correlation analyses, after applying the sample survey weights. All set correlation data analyses automatically used list wise deletion for missing data points.

Data recoding

Prior to running the SEM and set correlation analyses several variables were recoded. This recoding was consistent with Cohen's recommendations of limiting the number of variables to those most conceptually substantive (269). Histograms were created in SPSS to visually examine the variables.

In the biological-biomedical domain, gender was recoded into a dummy variable with female = 1 and male = 0. The comorbid somatic conditions (asthma, diabetes,

arthritis, hypertension, heart disease and stroke) were dichotomized as yes (1) or no (0) which were added together into a summary score (total number of comorbid somatic conditions) ranging from 0 to 6.

In the psychological domain, the variables for mood and anxiety disorders were also recoded as dummy variables (yes = 1, no = 0). The variable, number of mental health professional visits in the past year was created by combining the separate variables representing the number of visits to a social worker/counselor in the last one year and number of visits to a psychologist in the last one year.

In the social domain, employment status was recoded as a dummy variable (yes = 1, no = 0). The marital status variable was created by combining married and common-law categories. This variable was then recoded as a dummy variable (married/common-law marriage = 1 and single/never married/separated/divorced/widowed = 0). Sense of belonging to the community was recoded from very strong (1) to very weak (4) into very weak (1) to very strong (4) to better capture a positive association between quality of life and connection to the community.

Structural equation modeling (SEM)

Originally SEM was the first method of analysis chosen. SEM allows for a determination of the extent to which measures in a model are reliable and then separately accounts for the unexplained variance in the factors (270). Theoretically, SEM also allows examination of the relationships between each of the three constructs in the biopsychosocial model. SEM has the ability to test a conceptual and a measurement model at the same time. SEM can also test the latent variable structure as well as allow

for multiple measures of both the independent and dependent variables while adjusting for measurement error (270).

Based on a proposed measurement model to examine a priori hypotheses about relationships between the observed variables and the latent constructs, several preliminary SEM analyses were conducted. These preliminary analyses revealed significant issues with multivariate normality for several variables (number of comorbid somatic conditions, number of family doctor/primary care visits in the past year and number of mental health visits to a psychologist/social worker in the past year). This was consistent with the visual information gleaned from the histograms.

The preliminary SEM analyses also revealed that significant transformation of variables would not be sufficient based on the Satorra-Bentler test statistic (271). Log transformation would also necessitate very complicated explanations of the transformed variables. Lastly, based on conversations with a statistical consultant (Gerald Bean), several important constructs in the social domain (annual income, education and employment status) were not feasible in the causal framework of SEM. Conceptually it is not consistent to have these demographics as “causal” factors in an SEM measurement model.

Since SEM is a confirmatory approach it is most often used to test theory based on prior knowledge or hypotheses about potential relationships between variables. The preliminary models suggested a need to run multiple models. The use of the resultant multiple fit indices to identify ways of improving the model would have lead to a series of changes in the model. This particular approach is not recommended as it moves SEM

from a confirmatory method to an exploratory method (271, 272). The combination of these untenable factors created a need to re-assess the chosen method for analysis.

In such situations SEM compares unfavorably to more conventional statistical procedures such as ordinary least squares regression which allow for a more comprehensive and rigorous evaluation of a model fit (such as R^2 values) than SEM (271). However the use of traditional regression analyses (linear or logistic) with multiple dependent variables would also require a significant increase in the number of statistical tests resulting in a substantial increase in the Type I error rate. As part of the process I was informed about another analysis method called set correlation that would be more appropriate for the analysis of multiple dependent variables. The use of set correlation may also help suggest potential moderation effects however no conclusions with regards to causality can be made using this approach and with this cross-sectional research design.

Set correlation

Typical multivariate methods focus on multiple independent variables and one dependent variable. Set correlation, on the other hand, is a general scheme for studying the relationships between two sets of variables, X and Y, containing any number of variables of any type in each set (273). This allows for the study of the association between research factors unconstrained by level of measurement or form of the relationship (274). This includes nominal (qualitative) scales, curvilinearly related quantitative (ratio, interval, ordinal) scales, interaction, contrasts and missing data (275). The same assumptions underlying ANOVA, linear regression and other linear models are

appropriate for set correlation. Thus if variables have a nonlinear relationship transformation is usually recommended (276).

Cohen, Cohen, West and Aiken (2003) in their text *Applied Multivariate Regression/Correlation for the Social Sciences* identify four properties of set correlation: 1) it is a truly multivariate multiple regression/correlation (MRC) analysis that can employ the structural features of MRC (such as hierarchical entry of variables) with dependent research factors of any kind, 2) set correlation bears the same relationship to standard ordinary least squares that MRC does to standard OLS univariate methods (therefore MANOVA, MANCOVA and discriminant analysis are just special cases of set correlation) (277), 3) it generally frees the analysis from the MANOVA requirement of nominal scale research factors, making possible multivariate analysis of partial variance, multivariate significance tests and other novel analysis methods and 4) set correlation provides a single framework of measures of association, parameter estimation, hypothesis testing and statistical power analysis that are part of standard data analysis methods (p. 609) (269).

Set correlation is also appropriate for the analysis of the relationship between two categorical (nominal scales) variables and their joint frequencies (273, 278). The advantage of set correlation in the analysis of cross-tabulations lies in its ability to follow up the analysis of the overall association with contrasts and partialling to identify where the association is coming from (278). This is typically done through the use of dummy coding for each nominal scale. By bringing nominal scales into set correlation they “can be analyzed in a common framework of correlational analysis with quantitative scales” (p. 343) (274).

Partialling

Partialling (or residualization) is a powerful device that allows the researcher to statistically control for variables or covariates (like ANCOVA). It is also useful for representing interactions, curvilinear components, contrasts among groups as well as to represent the uniqueness of a variable or a set of variables (273, 275). By use of partialling, set correlation assesses specific hypotheses about the detail of an association by providing measures of the strength of the association (correlations) but also significance tests, estimation and power analysis all within a unified framework that can systematically study relationships among phenomena unconstrained by the level of measurement (273).

Partialling a set of “A” variables from the set “B” variables produces a new set “B*A”, whose variables now have zero correlation with those in set “A”. These A-partialled B variables are the result of when each variable in set “B” is subtracted from the value predicted for it by the multiple regression equation. Each partialled variable in set B is considered the residual after that part that is linearly related to set “A” has been removed (275). This results in five different types of association based on which side (or not) the analyst decides to partial variables on (269). This flexibility in set correlation has been summarized by Cohen as “with it you can study the relationship between anything and anything else, controlling for what you what in either the anything or the anything else, or both” (p. 1311) (279).

Partialling increases statistical power by helping to eliminate irrelevant variance that would otherwise be treated as error variance (275). Partialling can also be used as a

type of purification of a variable to its uniqueness. This is often utilized when analyzing the effects and independence of a subscale from other subscales (269).

Multiple R^2 (multivariate $R^2_{Y,X}$)

The common framework of set correlation includes a common measure of the magnitude of relationship (275). The multiple R^2 (or multivariate $R^2_{Y,X}$) is interpretable as a proportion of generalized variance (274). This represents the relationship or “overlap” between the set of independent variables and the set of dependent variables and is symmetrical (yields the same value for X related to Y as for Y related to X) and is bounded by 0 and 1 (275). To address the potential positive bias (overestimation) of the population multiple R^2 by its sample, set correlation analysis in Systat also provides a “shrunk” R^2 . The bias in R^2 decreases as number of cases increases with the numerator df of the F test (269).

Set correlation also provides other measures of multivariate association that can be used as part of the partialling function. These include the proportion of additive variance which has been called trace correlation (275) or symmetric T^2 . Symmetric T^2 is the proportion of set Y additive variance accounted for by set X and is regarded as measuring the average effect. It is less useful when the set Y defines a single construct as the investigator does not wish to average over the combination of elements which are best summarized by $R^2_{Y,X}$ (275). Set correlation also provides another associational measure called “symmetric P^2 squared trace correlation” as another measure of additive variance (269).

These measures of overall association demonstrate the significant strength of set correlation over canonical correlation. Like set correlation, canonical correlation helps

the researcher examine the complex interactions of data on two sets of variables (280) by maximizing the correlation between the two linear functions (281). However, canonical correlations do not provide a single measure of the strength of the association such as R^2 (275). In addition, examination of multiple pairs of canonical factors has limited utility in understanding the nature of the X, Y relationship (269). Also, set correlation works with the original variables and not rotated versions in carving out “the overall association between substantively meaning components” (p. 610) (269).

Significance test

The recommended significance test for $R^2_{Y,X}$ in set correlation is the Rao F test, an approximate test when the numbers of variables in the two sets of variables both exceed two (278). The Rao F test specializes to the standard null hypothesis in the F test for the multiple R^2 that is calculated as part of set correlations (273). The Rao F test also specializes to the more familiar F test in multiple correlation/regression and analysis of variance when either set has only one variable (278).

A multivariate significance test treats the variables in a set simultaneously by taking into account the correlations among the variables, thus providing different information than what would be obtained from a series of univariate tests on the individual variables (269). The multivariate test has the virtue of providing a valid null hypothesis test when all the population multiple R^2 of the individual Y variables with the set of X variables are zero (269).

Standardized Beta weights

Set correlation also provides standardized beta weights which are analogous to those obtained as standard partial regression weights in multiple linear regression (269).

In this way variables in a set can be compared to each other to determine which variables contribute the most, just as predictor variables are compared in linear regression in order to determine the variables that contribute the most to the prediction. The standardized beta weights in set correlation are partial regression weights that partial out the unique contribution of each variable.

Statistical power and sample size

In set correlation (and multivariate methods in general) a power analysis is more complex than those calculated for hypothesized mean or proportion differences in that the effect size is not a simple function of a measure of association. Power increases as the strength of association increases but decreases with the number of variables in each set and is also of course influenced by sample size (n) and the alpha rejection level (α) (269).

Based on the tables in Cohen's classic book *Statistical Power Analysis for the Behavioral Sciences* and tables provided in his other texts (269, 282) the sample size for this study ($n = 1,702$) is > 500 cases as presented in Cohen's writings. Samples > 500 yield a power calculation $> .99$ for $R^2_{Y,X}$ values from 0.20 to 0.40. This power holds for set sizes of as much as 16 variables on each side using either an α set at 0.05 or 0.01 (269, 282). Cohen also reminds the reader that $R^2_{Y,X}$ values are population values and the $R^2_{Y,X}$ values seen in samples are positively biased, so the investigator should utilize the shrunken $R^2_{Y,X}$ in setting estimates for power analysis (269).

Cohen also recommended several steps to guard against experiment-wise Type I error inflation in set correlation. These include: 1. avoid the use of more variables or more sets of variables than are needed to frame the issue: "less is more", 2. distinguish between confirmatory (conclusion-seeking) and exploratory research. As the exploratory

approach produces hypotheses for further research then Type I error inflation is not as grave of an issue, 3. when possible combine research factors into larger sets and require that the latter be statistically significant as a condition of testing the former, 4. use a Bonferroni approach or 5. use a more stringent criteria for each test (275).

Use of set correlation in the published literature

Set correlation, while not abundant in the literature, has been used in a wide array of studies in the social sciences, especially in the field of psychology. These include; personality factors and relationship between informal reasoning in economic issues (283), psychological profiling of sexual murders (284), the effect of peers and the moderating role of father absence and the mother-child relationship on adolescent problem behavior (285), the theory of production competence in production management (286), the relationship between athletic satisfaction and intra-team communication in the area of group dynamics (287) and the relationship between pain, neuropsychological performance and physical function in older adults with chronic low back pain (288). Set correlation has also been used in the natural sciences to examine evolution of phenotypic integration in six species of Brassica (flowering plants in the Mustard family) (289).

Set correlation analysis of the biopsychosocial model

Whole set correlation

First, the three components of the biopsychosocial model (biological-biomedical, psychological and social) are utilized as independent variables via the whole set correlation analysis procedure. See Table 5. Results are summarized as the variance explained in the form of a multiple R^2 statistic. Second, examination of the individual standardized beta weights for each latent variable (the biological-biomedical,

psychological and social domains) reveals specific patterns of independent variables that best explain quality of life. Lastly, the full biopsychosocial model was tested via the whole set correlation analysis (Y vs. X) by the inclusion of all the variables within the three domains. The full model examined the association between all the independent variables and the three dependent variables (self-rated health status, self-rated mental health status and life satisfaction).

Semipartial and partial set correlation

To further examine the explained variance in the individual domains a series of partialled set correlations were conducted, see Table 6. The purpose was to examine the change in multiple R^2 when various domains were controlled for via partialling. In this analysis the independent variables from the other domains are controlled for: 1. only on the independent side of the variable set (X semipartial: Y vs. X/X partial), 2. only on the dependent side of the variable set (Y semipartial: Y/partial vs. X) and 3. on both the independent and dependent side of the variable set (Partial set correlation: Y/Y partial vs. X/X partial, where Y partial = X partial).

First, semipartial and partial set correlation analyses were used to test the association between the independent variables in the biological-biomedical domain while controlling for the psychological and social domains. Second, semipartial and partial set correlation analyses were used to test the association between the independent variables in the psychological domain while controlling for the biological-biomedical and social domains. Third, semipartial and partial set correlation analyses were used to test the association between the independent variables in the social domain while controlling for the biological-biomedical and psychological domains.

Chapter IV: Results

Descriptive Statistics

There were a total of $n = 1,702$ epilepsy cases in the combined CCHS 2.1 and CCHS 3.1 samples, see Table 1. Descriptively, the largest proportion of the epilepsy sample comes from the provinces of Ontario ($n = 504$) 33.5% (95%CI: 28.0-39.1) and Quebec ($n = 419$) 28.5% (95%CI: 22.9-34.1). This is followed by British Columbia ($n = 201$) 13.5% (95%CI: 9.5-17.4) and Alberta ($n = 122$) 9.4% (95%CI: 5.8-13.0). The remaining provinces Saskatchewan, Manitoba, New Brunswick, Nova Scotia, Newfoundland and Labrador, Yukon, Northwest Territories, Nunavut and Prince Edward Island had sample sizes of less than 100. The sample frame consisted of $n = 904$ cases from the area frame, $n = 794$ cases from the phone frame list and $n < 30$ cases from the phone frame random-digit dialing method. Of the 1,702 cases in the sample ($n = 170$) 13.4% (95% CI: 9.2-17.5) were interviewed by proxy.

Table 1. Sample Description, CCHS 2.1 and 3.1 (n = 1702)

	% (n) 95%CI
Province	
Newfoundland and Labrador	2.0 (64) [0.9-3.0]
Prince Edward Island	0.3 (<30) [0.07-0.57]
Nova Scotia	2.9 (72) [1.5-4.3]
New Brunswick	2.9 (81) [1.6-4.2]
Quebec	28.5 (419) [22.9-34.1]
Ontario	33.5 (504) [28.0-39.1]
Manitoba	3.4 (87) [1.8-5.2]
Saskatchewan	3.2 (99) [1.8-4.6]
Alberta	9.4 (122) [5.8-13.0]
British Columbia	13.5 (201) [9.5-17.4]
Yukon, Northwest Territories, Nunavut	0.3 (31) [0.08-0.60]
Sample type	
Area frame	47.9 (904) [42.1-53.7]
Phone frame list	52.1 (794) [46.3-57.9]
Phone frame RDD	0.03 (< 30) [-0.02-0.09]
Interview type (Area frame only)	
On telephone	11.9 (211) [8.5-15.4]
In person	34.2 (659) [28.7-39.8]
Both	1.2 (< 30) [0.2-2.3]
Not stated	0.5 (< 30) [-0.06-1.03]
Not applicable	52.1 (798) [46.3-57.9]
Interview by proxy	13.4 (170) [9.2-17.5]

Descriptive statistics of the epilepsy populations are presented in Table 2. Of the 1,702 cases in the combined sample, n = 835 were from the CCHS 2.1 (2003 wave) and n = 867 from the CCHS 3.1 (2005 wave). The epilepsy prevalence rate for the CCHS 2.1 was 0.57% (95%CI: 0.47-0.67) and 0.59% (95%CI: 0.50-0.68) for the CCHS 3.1. The sample is primarily Caucasian, 86.2% (95%CI: 80.0-92.5) for the CCHS 2.1 and 87.3% (95%CI: 82.3-92.4) for the CCHS 3.1. The descriptive statistics are further broken down by the biological-biomedical, psychological and social domains. There were no significant differences on any of the variables based on non-overlapping 95%CIs between the CCHS 2.1 wave and the CCHS 3.1. This is consistent with previous investigations that combined multiple waves of the CCHS to look at PWE (266). The descriptive statistics of the combined sample are presented in Table 3. These represent the re-coded variables used in the analyses.

Table 2. Descriptive statistics of persons with epilepsy CCHS 2.1 and CCHS 3.1

Variables	CCHS 2.1 (n = 835) %/Mean (95%CI)	CCHS 3.1 (n = 867) %/Mean (95%CI)
Epilepsy Prevalence	0.57 (0.47-0.67)	0.59 (0.50-0.68)
Caucasian	86.2 (80.0-92.5)	87.3 (82.3-92.4)
<u>Biological-Biomedical</u>		
<u>Age</u>		
12-24	21.8 (14.1-29.5)	18.2 (12.3-24.1)
25-39	18.7 (12.8-24.6)	24.9 (18.5-31.4)
40-54	30.6 (22.6-38.6)	32.3 (24.3-40.2)
55-69	16.6 (9.8-23.5)	16.3 (11.1-21.5)
≥ 70	12.3 (6.4-18.2)	8.3 (4.7-12.0)
<u>Gender</u>		
Male	50.9 (42.2-59.6)	47.0 (39.2-54.8)
Female	49.1 (40.4-57.8)	53.0 (45.2-60.8)
<u>Comorbid Somatic Conditions</u>		
Asthma	11.8 (6.6-17.1)	13.1 (7.9-18.3)
Diabetes	4.6 (1.7-7.4)	8.4 (2.6-14.1)
Arthritis	23.9 (16.9-30.8)	25.4 (18.3-32.5)
Hypertension	13.2 (8.3-18.1)	15.9 (10.5-21.3)
Heart Disease	9.6 (5.5-13.7)	7.2 (3.4-10.9)
Stroke	6.4 (2.7-10.0)	6.5 (3.3-9.8)
Number of Family Doctor/General Practitioner visits (past 1 year)	6.5 (4.0-9.0)	6.3 (4.3-8.3)
<u>Psychological</u>		
<u>Self-perceived life stress</u>		
Not at all	13.2 (6.2-20.2)	11.9 (6.9-16.8)
Not very	16.2 (10.7-21.6)	18.5 (12.8-24.2)
A bit	38.6 (30.0-47.2)	36.0 (28.6-43.4)
Quite a bit	22.5 (15.2-29.9)	22.4 (15.2-29.7)
Extremely	5.3 (2.1-8.5)	5.9 (2.3-9.4)
Mood Disorder	12.1 (6.7-17.4)	11.7 (7.3-16.1)
Anxiety Disorder	8.6 (4.0-13.2)	12.7 (7.0-18.5)
<u>Number of mental health professional visits (past 1 year)</u>		
Psychologist	0.7 (-0.1-1.5)	0.4 (0.1-0.6)
Social Worker	0.9 (0.4-1.5)	1.3 (-0.01-2.65)
<u>Social</u>		
<u>Education</u>		
Less than secondary	40.2 (31.3-49.0)	30.9 (24.3-37.5)
Secondary graduate	19.1 (12.6-25.6)	15.7 (10.3-21.0)
Other post-secondary	7.8 (3.4-12.2)	7.9 (3.3-12.5)
Post-secondary graduate	31.2 (23.5-38.9)	39.6 (31.7-47.6)
<u>Annual Income</u>		
No income	10.7 (7.0-14.4)	10.2 (6.6-13.9)
15,000-29,999	17.3 (11.6-23.1)	18.1 (11.7-24.5)
30,000-49,999	18.0 (10.7-25.3)	16.7 (11.0-22.4)
50,000-79,999	17.7 (10.4-25.0)	18.0 (12.0-23.9)
80,000 or more	17.7 (11.0-24.4)	19.4 (12.6-26.2)
Worked in past 12 months	47.1 (38.3-55.9)	49.6 (41.8-57.4)
<u>Marital Status</u>		
Married	36.4 (28.3-44.5)	40.6 (32.6-48.6)
Common-law	9.1 (2.4-15.8)	8.4 (4.0-12.9)
Widowed/Separated/Divorced	14.1 (8.2-20.0)	13.4 (8.6-18.2)
Single/Never married	40.3 (31.7-48.8)	37.5 (30.3-44.8)
<u>Sense of belong to community</u>		
Very strong	15.6 (8.9-22.3)	15.2 (10.0-20.3)
Somewhat strong	30.5 (22.7-38.3)	37.3 (29.7-44.9)
Somewhat weak	23.9 (16.8-30.9)	24.2 (17.1-31.4)
Very weak	15.7 (8.8-22.5)	9.4 (5.6-13.2)

Table 3. Descriptive statistics of persons with epilepsy in combined sample, CCHS 2.1 and CCHS 3.1, (n = 1702)

Variables	%/Mean (95%CI)
<u>Biological-Biomedical</u>	
Age	
12-24	19.9 (15.1-24.8)
25-39	21.9 (17.5-26.3)
40-54	31.5 (25.8-37.1)
55-69	16.5 (12.2-20.7)
≥ 70	10.2 (6.8-13.7)
Gender	
Male	48.9 (43.1-54.8)
Female	51.1 (45.2-56.9)
Total Number of Comorbid Somatic Conditions	
0	56.9 (51.1-62.6)
1	26.2 (21.1-31.4)
2	10.2 (7.1-13.3)
3	4.3 (1.7-6.9)
4	1.5 (0.5-2.6)
5	0.6 (-0.3-1.5)
6	0.3 (-0.3-0.9)
Number of Family Doctor/General Practitioner visits (past 1 year)	6.4 (4.8-8.0)
<u>Psychological</u>	
Self-perceived life stress	
Not at all	12.5 (8.3-16.8)
Not very	17.4 (13.4-21.3)
A bit	37.3 (31.6-42.9)
Quite a bit	22.5 (17.4-27.6)
Extremely	5.6 (3.2-8.0)
Mood Disorder	11.9 (8.4-15.3)
Anxiety Disorder	10.7 (7.0-14.5)
Number of mental health professional (social worker/counselor and/or psychologist) visits (past 1 year)	1.0 (0.7-1.4)
<u>Social</u>	
Education	
Less than secondary	35.4 (29.8-41.0)
Secondary graduate	17.3 (13.2-21.5)
Other post-secondary	7.9 (4.7-11.1)
Post-secondary graduate	35.5 (29.9-41.2)
Annual Income	
No income	10.5 (7.9-13.0)
15,000-29,999	17.7 (13.4-22.0)
30,000-49,999	17.4 (12.8-22.0)
50,000-79,999	17.8 (13.2-22.5)
80,000 or more	18.6 (13.8-23.4)
Not stated	18.0 (13.5-22.6)
Worked in past 12 months	48.4 (42.5-54.2)
Marital Status	
Married/ Common-law	52.6 (46.7-58.5)
Widowed/Separated/Divorced/Single/Never married	47.3 (41.5-53.2)
Sense of belong to community	
Very strong	15.4 (11.2-19.6)
Somewhat strong	34.0 (28.5-39.5)
Somewhat weak	24.1 (19.0-29.1)
Very weak	12.4 (8.5-16.4)

Correlations

Table 4 displays the Between Basic y (three dependent variables) and Basic x (independent variables) for the individual domains of the biopsychosocial model as well as the full biopsychosocial model. SYSTAT does not display the p-values as part of this analysis. The correlational analysis does however demonstrate no issue with multicollinearity between the variables.

Biological-biomedical domain

In the biological-biomedical domain, the independent variables: total number of comorbid somatic conditions ($r = -0.41$), total number of family doctor/general practitioner visits in the past 1 year ($r = -0.30$) and age ($r = -0.21$) had the strongest correlations with the self-rated health status variable. Total number of comorbid somatic conditions also correlated with self-rated mental health status ($r = -0.27$) and life satisfaction ($r = -0.24$).

Psychological domain

In the psychological domain, the independent variables: self-perceived life stress ($r = -0.29$), mood disorder ($r = -0.39$), anxiety ($r = -0.31$) and total number of mental health professional visits in the past year ($r = -0.23$) correlated most strongly with the self-rated mental health status. Self-perceived life stress is moderately correlated with self-rated health status ($r = -0.23$) and life satisfaction ($r = -0.31$). Mood disorder is also moderately correlated with self-rated health status ($r = -0.33$) and life satisfaction ($r = -0.32$).

Social domain

In the social domain, education correlated most strongly with self-rated health status ($r = 0.18$). Annual household income is correlated moderately with all three dependent variables, self-rated health status ($r = 0.30$), self-rated mental health status ($r = 0.22$) and life satisfaction ($r = 0.27$). Employment status is also moderately correlated with all three dependent variables, self-rated health status ($r = 0.33$), self-rated mental health status ($r = 0.27$) and life satisfaction ($r = 0.22$). Marital status (defined as married/common-law) was most correlated with life satisfaction. Sense of belonging to the community also correlated most strongly with life satisfaction ($r = 0.27$).

Full biopsychosocial model

In the full biopsychosocial model, total number of comorbid somatic conditions was moderately correlated with all three dependent variables; self-rated health status ($r = -0.41$), self-rated mental health status ($r = -0.32$) and life satisfaction ($r = -0.29$). Total number of family doctor/general practitioner visits in the past year correlated most with self-rated health status ($r = -0.33$).

Self-perceived life stress was moderately correlated with self-rated mental health status ($r = -0.35$) and life satisfaction ($r = -0.32$). Mood disorder remained moderately correlated with all three dependent variables; self-rated health status ($r = -0.30$), self-rated mental health status ($r = -0.42$) and life satisfaction ($r = -0.33$). Anxiety disorder was moderately correlated with all three dependent variables; self-rated health status ($r = -0.25$), self-rated mental health status ($r = -0.34$) and life satisfaction ($r = -0.20$). Total number of mental health professional visits in the past 1 year remained correlated most with the self-rated mental health status ($r = -0.25$).

Of the social variables, education was mildly correlated with self-rated health status ($r = 0.18$). Annual household income was moderately correlated with all three dependent variables; self-rated health status ($r = 0.29$), self-rated mental health status ($r = 0.22$) and life satisfaction ($r = 0.27$) as was employment status; self-rated health status ($r = 0.32$), self-rated mental health status ($r = 0.27$) and life satisfaction ($r = 0.22$). Marital status was most correlated with life satisfaction ($r = 0.23$) and sense of belonging to the community was mildly correlated with all three dependent variables; self-rated health status ($r = 0.14$), self-rated mental health status ($r = 0.18$) and life satisfaction ($r = 0.25$).

Table 4. Correlations between the biopsychosocial model and quality of life

Model	Correlations		
	Self-rated health status	Self-rated mental health status	Life satisfaction
<u>Biological-Biomedical</u> (n = 1,485)			
Age	-0.21	0.001	-0.01
Gender (Female)	-0.04	-0.01	-0.04
Total number of comorbid somatic conditions	-0.41	-0.27	-0.24
Number of Family Doctor/General Practitioner visits (past 1 year)	-0.30	-0.14	-0.10
<u>Psychological</u> (n = 1,448)			
Self-perceived life stress	-0.23	-0.29	-0.31
Mood disorder	-0.33	-0.39	-0.32
Anxiety disorder	-0.22	-0.31	-0.19
Number of mental health professional visits (past 1 year)	-0.08	-0.23	-0.12
<u>Social</u> (n = 1,139)			
Education	0.18	0.06	0.08
Annual household income	0.30	0.22	0.27
Worked in past 12 months	0.33	0.27	0.22
Married/Common law	0.10	0.12	0.23
Sense of belonging to the community	0.15	0.19	0.27
<u>Full Biopsychosocial Model</u> (n = 1,118)			
Age	-0.15	0.01	-0.04
Gender (Female)	-0.02	-0.04	-0.04
Total number of comorbid somatic conditions	-0.41	-0.32	-0.29
Number of Family Doctor/General Practitioner visits (past 1 year)	-0.33	-0.17	-0.14
Self-perceived life stress	-0.19	-0.35	-0.32
Mood disorder	-0.30	-0.42	-0.33
Anxiety disorder	-0.25	-0.34	-0.20
Number of mental health professional visits (past 1 year)	-0.12	-0.25	-0.10
Education	0.18	0.06	0.08
Annual household income	0.29	0.22	0.27
Worked in past 12 months	0.32	0.27	0.22
Married/Common law	0.11	0.13	0.23
Sense of belonging to the community	0.14	0.18	0.25

Whole set correlation Y vs. X

Biological-biomedical domain

The multiple R^2 for the biological-biomedical domain explained 24.8% (shrunken $R^2 = 24.2\%$) of the variance in the three dependent variables, Rao $F(12, 3910) = 37.05$, $p \leq 0.001$, see Table 5. In the biological-biomedical domain, age had a negative association with self-rated health status (beta = -0.07, $p = 0.006$) but a positive association with self-rated mental health status (beta = 0.12, $p \leq 0.001$) and life satisfaction (beta = 0.09, $p = 0.001$). In the biological-biomedical domain, gender was not associated with any of the three dependent variables. Total number of comorbid somatic conditions had a negative association with all three quality of life measures; self-rated health status (beta = -0.32, $p \leq 0.006$), self-rated mental health status (beta = 0.30, $p \leq 0.001$) and life satisfaction (beta = -0.26, $p \leq 0.001$). The number of family doctor/primary care visits in the past year was most associated with self-rated health status (beta = -0.21, $p \leq 0.001$) but much less associated with self-rated mental health status (beta = -0.07, $p = 0.004$).

Psychological domain

The multiple R^2 for the psychological domain explained 30.4% (shrunken $R^2 = 29.8\%$) of the variance in the three dependent variables, Rao $F(12, 3812) = 46.61$, $p \leq 0.001$. In the psychological domain, self-perceived life stress had a negative association with quality of life across all 3 dependent variables; self-rated health status (beta = -0.14, $p \leq 0.001$), self-rated mental health status (beta = -0.18, $p \leq 0.001$) and life satisfaction (beta = -0.24, $p \leq 0.001$). The presence of a mood disorder was also negatively associated with all three dependent variables; self-rated health status (beta = -0.26, $p \leq$

0.001), self-rated mental health status (beta = -0.26, $p \leq 0.001$) and life satisfaction (beta = -0.23, $p \leq 0.001$). Presence of an anxiety disorder revealed a negative association with self-rated health status (beta = -0.10, $p \leq 0.001$) and self-rated mental health status (beta = -0.15, $p \leq 0.001$) but not life satisfaction. The number of mental health professional visits (social worker/counselor and/or psychologist) in the past 1 year was only associated with self-rated mental health status (beta = -0.12, $p \leq 0.001$).

Social domain

The multiple R^2 for the social domain explained 26.0% (shrunk $R^2 = 25\%$) of the variance in the three dependent variables, Rao F (15, 3122) = 23.96, $p \leq 0.001$. In the social domain, education had a weak positive association with self-rated health status (beta = 0.07, $p = 0.015$) and no association on the other quality of life measures. Annual household income was positively associated with all three dependent variables; self-rated health status (beta = 0.17, $p \leq 0.001$), self-rated mental health status (beta = 0.11, $p = 0.002$) and life satisfaction (beta = 0.17, $p \leq 0.001$). Being employed was also positively associated with all three dependent variables; self-rated health status (beta = 0.22, $p \leq 0.001$), self-rated mental health status (beta = 0.22, $p \leq 0.001$) and life satisfaction (beta = 0.11, $p \leq 0.001$). Marital status was significant only with regards to life satisfaction (beta = 0.13, $p \leq 0.001$). Sense of belonging to the community was positively associated with all three dependent variables; self-rated health status (beta = 0.13, $p \leq 0.001$), self-rated mental health status (beta = 0.17, $p \leq 0.001$) and life satisfaction (beta = 0.24, $p \leq 0.001$).

Full biopsychosocial model

The multiple R^2 for the full biopsychosocial model explained 55.0% (shrunken $R^2 = 53.4\%$) of the variance in the three dependent variables, Rao $F(39, 3264) = 25.93$, $p \leq 0.001$). For the biological-biomedical variables, age was positively associated with self-rated mental health status ($\beta = 0.07$, $p = 0.024$). Female gender was mildly associated of all three dependent variables; self-rated health status ($\beta = 0.07$, $p = 0.007$), self-rated mental health status ($\beta = 0.08$, $p = 0.002$) and life satisfaction ($\beta = 0.07$, $p = 0.011$). Total number of comorbid somatic conditions was negatively associated with all three quality of life measures; self-rated health status ($\beta = -0.21$, $p \leq 0.001$), self-rated mental health status ($\beta = -0.10$, $p = 0.004$) and life satisfaction ($\beta = -0.16$, $p \leq 0.001$). The number of family doctor/primary care visits in the past 1 year was only associated with self-rated health status ($\beta = -0.22$, $p \leq 0.001$) in the full model.

In the psychological domain, self-perceived life stress was negatively associated with all three dependent variables; self-rated health status ($\beta = -0.14$, $p \leq 0.001$), self-rated mental health status ($\beta = -0.23$, $p \leq 0.001$) and life satisfaction ($\beta = -0.26$, $p \leq 0.001$). Having a mood disorder was also negatively associated with all three dependent variables; self-rated health status ($\beta = -0.10$, $p = 0.001$), self-rated mental health status ($\beta = -0.23$, $p \leq 0.001$) and life satisfaction ($\beta = -0.16$, $p \leq 0.001$). In the full model, anxiety disorder had a negative association only with self-rated mental health status ($\beta = -0.09$, $p = 0.005$). The number of mental health professional visits in the past 1 year was associated only with self-rated mental health status ($\beta = -0.11$, $p \leq 0.001$).

For the social variables, education status had a mild positive association only with self-rated health status ($\beta = 0.07$, $p = 0.015$). Annual household income was positively

associated with all three dependent variables; self-rated health status (beta = 0.11, $p \leq 0.001$), self-rated mental health status (beta = 0.08, $p = 0.011$) and life satisfaction (beta = 0.13, $p \leq 0.001$). Being employed was positively associated with self-rated health status (beta = 0.09, $p = 0.004$) and self-rated mental health status (beta = 0.16, $p \leq 0.001$). Martial status remained significantly associated only with life satisfaction (beta = 0.15, $p \leq 0.001$). Sense of belonging to the community was positively associated with all three dependent variables; self-rated health status (beta = 0.10, $p \leq 0.001$), self-rated mental health status (beta = 0.09, $p \leq 0.001$) and life satisfaction (beta = 0.19, $p \leq 0.001$).

Table 5. Whole set correlation (Y vs. X) results for the biopsychosocial model and quality of life

Model	Multiple R ²	Standardized Beta Weights		
		Self-rated health status	Self-rated mental health status	Life satisfaction
<u>Biological-Biomedical</u> (n = 1,485)	24.8%***			
Age		-0.07**	0.12***	0.09***
Gender (Female)		-0.01	0.01	-0.02
Total number of comorbid somatic conditions		-0.32***	-0.30***	-0.26***
Number of Family Doctor/General Practitioner visits (past 1 year)		-0.21***	-0.07**	-0.03
<u>Psychological</u> (n = 1,448)	30.4%***			
Self-perceived life stress		-0.14***	-0.18***	-0.24***
Mood disorder		-0.26***	-0.26***	-0.23***
Anxiety disorder		-0.10***	-0.15***	-0.05
Number of mental health professional visits (past 1 year)		-0.01	-0.12***	-0.02
<u>Social</u> (n = 1,139)	26.0%***			
Education		0.07*	-0.04	-0.03
Annual household income		0.17***	0.11**	0.17***
Worked in past 12 months		0.22***	0.22***	0.11***
Married/Common law		-0.01	0.04	0.13***
Sense of belonging to the community		0.13***	0.17***	0.24***
<u>Full Biopsychosocial Model</u> (n = 1,118)	55.0%***			
Age		-0.05	0.07*	-0.03
Gender (Female)		0.07**	0.08***	0.07*
Total number of comorbid somatic conditions		-0.21***	-0.10**	-0.16***
Number of Family Doctor/General Practitioner visits (past 1 year)		-0.22***	-0.03	-0.03
Self-perceived life stress		-0.14***	-0.23***	-0.26***
Mood disorder		-0.10***	-0.23***	-0.16***
Anxiety disorder		0.01	-0.09**	0.03
Number of mental health professional visits (past 1 year)		-0.01	-0.11***	0.04
Education		0.10***	-0.01	0.01
Annual household income		0.11***	0.08*	0.13***
Worked in past 12 months		0.09**	0.16***	0.04
Married/Common law		0.03	0.01	0.15***
Sense of belonging to the community		0.10***	0.09***	0.19***

Notes: * $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$

Partialled set correlation results

Biological domain

In the biological-biomedical domain, the whole set correlation multiple R^2 of 24.8% in Table 5 was reduced when the psychological domain independent variables were controlled for via partialling on the independent side (X semipartial: Y vs. X/X partial) $R^2 = 15.3\%$ (Shrunken $R^2 = 14.6\%$), the dependent side only (Y semipartial: Y/partial vs. X) $R^2 = 14.6\%$ (Shrunken $R^2 = 13.9\%$) and both the independent and dependent sides of the variable sets (Partial set correlation: Y/Y partial vs. X/X partial, where Y partial = X partial) $R^2 = 17.5\%$ (Shrunken $R^2 = 16.8\%$).

This same pattern was found when the independent variables in the social domain were partialled on only the independent side (X semipartial: Y vs. X/X partial) $R^2 = 17.5\%$ (Shrunken $R^2 = 16.6\%$), the dependent side only (Y semipartial: Y/partial vs. X) $R^2 = 18.5\%$ (Shrunken $R^2 = 17.6\%$), and both the independent and dependent sides of the variable sets (Partial set correlation: Y/Y partial vs. X/X partial, where Y partial = X partial) $R^2 = 20.8\%$ (Shrunken $R^2 = 20.0\%$).

When both the psychological and social domain variables were controlled for on the independent side (X semipartial: Y vs. X/X partial) the explained variance dropped to $R^2 = 11.1\%$ (Shrunken $R^2 = 10.1\%$), the dependent side only (Y semipartial: Y/partial vs. X) $R^2 = 11.1\%$ (Shrunken $R^2 = 10.1\%$) and both the independent and dependent sides of the variable sets (Partial set correlation: Y/Y partial vs. X/X partial, where Y partial = X partial) $R^2 = 14.3\%$ (Shrunken $R^2 = 13.3\%$).

Psychological domain

In the psychological domain, the whole set correlation multiple R^2 of 30.4% in Table 5 was reduced when the biological-biomedical domain independent variables were controlled for via partialling on only the independent side (X semipartial: Y vs. X/X partial) $R^2 = 19.7\%$ (Shrunken $R^2 = 19.0\%$), the dependent side only (Y semipartial: Y/partial vs. X) $R^2 = 20.6\%$ (Shrunken $R^2 = 19.9\%$) and both the independent and dependent sides of the variable sets (Partial set correlation: Y/Y partial vs. X/X partial, where Y partial = X partial) $R^2 = 22.7\%$ (Shrunken $R^2 = 22.0\%$).

A similar pattern was found when the independent variables in the social domain were partialled on only the independent side (X semipartial: Y vs. X/X partial) $R^2 = 25.8\%$ (Shrunken $R^2 = 25.0\%$), the dependent side only (Y semipartial: Y/partial vs. X) $R^2 = 29.4\%$ (Shrunken $R^2 = 28.7\%$) and both the independent and dependent sides of the variable sets (Partial set correlation: Y/Y partial vs. X/X partial, where Y partial = X partial) $R^2 = 31.0\%$ (Shrunken $R^2 = 30.2\%$).

When both the biological-biomedical domain and social domain variables were controlled for on the independent side (X semipartial) the explained variance dropped to $R^2 = 19.1\%$ (Shrunken $R^2 = 18.2\%$), the dependent side only (Y semipartial: Y/partial vs. X) $R^2 = 21.1\%$ (Shrunken $R^2 = 20.3\%$) and both the independent and dependent sides of the variable sets (Partial set correlation: Y/Y partial vs. X/X partial, where Y partial = X partial) $R^2 = 24.6\%$ (Shrunken $R^2 = 23.8\%$).

Social domain

In the social domain, the whole set correlation multiple R^2 of 26.0% in Table 5 was reduced when the biological-biomedical domain independent variables were controlled for via partialling only on the independent side (X semipartial: Y vs. X/X partial) $R^2 = 15.6\%$ (Shrunken $R^2 = 14.5\%$), the dependent side only (Y semipartial: Y/partial vs. X) $R^2 = 17.0\%$ (Shrunken $R^2 = 15.9\%$) and both the independent and dependent sides of the variable sets (Partial set correlation: Y/Y partial vs. X/X partial, where Y partial = X partial) $R^2 = 18.6\%$ (Shrunken $R^2 = 17.5\%$).

This same pattern was found when the independent variables in the psychological domain were partialled on only the independent side (X semipartial: Y vs. X/X partial) $R^2 = 16.9\%$ (Shrunken $R^2 = 15.7\%$), the dependent side only (Y semipartial: Y/partial vs. X) $R^2 = 19.9\%$ (Shrunken $R^2 = 18.8\%$) and both the independent and dependent sides of the variable sets (Partial set correlation: Y/Y partial vs. X/X partial, where Y partial = X partial) $R^2 = 21.3\%$ (Shrunken $R^2 = 20.2\%$).

When both the biological-biomedical domain and psychological domain variables were controlled for on the independent side (X semipartial: Y vs. X/X partial) the explained variance dropped to $R^2 = 13.5\%$ (Shrunken $R^2 = 12.3\%$), the dependent side only (Y semipartial: Y/partial vs. X) $R^2 = 16.3\%$ (Shrunken $R^2 = 15.2\%$) and both the independent and dependent sides of the variable sets (Partial set correlation: Y/Y partial vs. X/X partial, where Y partial = X partial) $R^2 = 18.5\%$ (Shrunken $R^2 = 17.4\%$).

Table 6. Partialled R² results for the biopsychosocial model and quality of life

Model	Whole set correlation Y vs. X	Multiple R ²		
		X semipartial Y vs. X/X partial	Y semipartial Y/Y partial vs. X	Partial Y/Y partial vs. X/X partial
Biological-Biomedical (n = 1,485)	24.8%***			
Psychological		15.3%***	14.6%***	17.5%***
Social		17.5%***	18.5%***	20.8%***
Psychological and Social		11.1%***	11.1%***	14.3%***
Psychological (n = 1,448)	30.4%***			
Biological-Biomedical		19.7%***	20.6%***	22.7%***
Social		25.8%***	29.4%***	31.0%***
Biological-Biomedical and Social		19.1%***	21.1%***	24.6%***
3 Social (n = 1,139)	26.0%***			
Biological-Biomedical		15.6%***	17.0%***	18.6%***
Psychological		16.9%***	19.9%***	21.3%***
Biological-Biomedical and Psychological		13.5%***	16.3%***	18.5%***
Full Biopsychosocial Model (n = 1,118)	55.0%***			

Notes: * $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$

Summary

The whole set correlation analysis demonstrated that the independent variables sets in each domain explained a significant amount of variance in the three quality of life measures: biological-biomedical (multiple $R^2 = 24.8\%$), psychological (multiple $R^2 = 30.4\%$) and social (multiple $R^2 = 26.0\%$).

However, the full biopsychosocial model explained quality of life in PWE (multiple $R^2 = 55.0\%$) better than the biological-biomedical model alone (multiple $R^2 = 24.8\%$). Results of the whole set correlation analyses provided more detail about the individual biopsychosocial domains and the associations of the variables with the three distinct measures of quality of life.

When the individual domains were examined via partial set correlation (a procedure that controls for the other domains on both the independent and dependent variable sets) the psychological (multiple $R^2 = 24.6\%$) and social domains (multiple $R^2 = 18.5\%$) still explained a greater amount of the variance in quality of life than the biological-biomedical model (multiple $R^2 = 14.3\%$).

As part of the analyses the psychological domain was tested without the number of mental health professional visits variable and with the variable. The addition of the number of mental health professional visits in past 1 year variable only contributed an additional 1% to multiple R^2 (29.5% versus 30.4%).

Chapter V: Discussion

The current study conceptually examined the biopsychosocial model through two research questions: 1) Is quality of life in PWE better explained by the biopsychosocial model than the biological-biomedical model? and 2) Does use of mental health services (social workers/counselors and psychologists) have a moderating effect on quality of life in PWE? I was also interested in examining potential moderating effects of the psychological and social domains on the biological-biomedical domain. Overall, my findings demonstrate that the biopsychosocial model explains quality of life in PWE better than the biological-biomedical model alone. The following hypothesis 1.1, 1.2 and 1.3 provide more specific details about how the biopsychosocial model may explain quality of life better than a biological-biomedical only approach.

Hypothesis 1.1. The individual domains (biological-biomedical, psychological and social) are all independently associated with quality of life.

My findings demonstrated the individual domains (biological-biomedical, psychological and social) were all independently associated with quality of life. The whole set correlation analysis demonstrated that the independent variables sets in each domain explained a statistically significant amount of variance in the three quality of life measures. A discussion of the individual domains and the influence of variables within each domain provide further explanations.

Biological-biomedical domain

Age

Age has a differential effect, depending on the quality of life measure being examined. Age has a negative influence on self-rated health status, but a positive influence on self-rated mental health and life satisfaction. Physical health declines with age so this finding is not unexpected as it is consistent with the aging process. Previous research suggests general measures of life satisfaction are not strongly related to objective life circumstances and lower levels of functioning are not always related to low levels of satisfaction (49). This may reflect the fact that people's expectations are based on changes in life circumstances. Therefore the positive association of age with self-rated mental health status and life satisfaction may suggest a differential adjustment to a diagnosis of epilepsy and its resulting effects over time. Clearly, cross-sectional research can only suggest an association. Prospective longitudinal research is needed to examine this further.

The impact of epilepsy on quality of life may reflect differences by age and time since diagnosis. A Veteran's Health Administration study of young, middle-aged, and older adults with epilepsy found young and middle-aged adults had higher physical functioning and poorer psychological functioning than older adults (290). These analyses included an interaction terms between age and epilepsy chronicity (chronic epilepsy, new-onset epilepsy and no epilepsy). When these significant interactions were accounted for, middle aged adults had the lowest scores regardless of epilepsy status. The findings may be a reflection of the difficulty that middle-aged adults may have in providing financial and emotional support to their family, mentoring of the younger generation and

support to aging parents while dealing with their epilepsy. In contrast, younger adults have more physiological reserves and fewer responsibilities and older adults have already begun to cope with decreases in health status because of other comorbid conditions (290).

The concerns of persons with new onset epilepsy in adulthood are different than those with epilepsy starting in childhood. New onset seizures in adulthood can trigger a complex adjustment process. One prospective study described the psychosocial adjustment process following newly diagnosed seizures found pervasive loss of control, anxiety and depression predicted subsequent seizure recurrence (106). In addition cognitive problems from seizures and/or their treatment can have problematic effects on the changing psychological and medical contexts and life adjustment to epilepsy as an adult (107).

A large prevalence study in the UK found few differences between older and younger people with regard to their reported quality of life (109). Younger people were however more likely to report feeling stigmatized. Persons with epilepsy diagnosed in later life were more anxious and depressed than those diagnosed earlier. Their overall perception of quality of life was also more likely to be negative (109). Other literature suggests, although often under-diagnosed and inadequately treated, depression and anxiety are common in elderly persons with epilepsy (110).

Gender

My findings suggest no differences in quality of life by gender in the biological-biomedical domain. The literature on gender and epilepsy has focused on the biomedical aspects and not quality of life. Previous research suggests while the overall incidence of epilepsy is slightly higher in males, females are more likely to have a generalized form of

epilepsy (a form of epilepsy that often involves more dramatic convulsions) (111). Several studies suggest females are more likely to be seen by a neurologist versus a general practitioner (112, 113) but this differential access to specialty care has not reduced the proportion of women with intractable epilepsy (uncontrolled seizures despite trials of more than two AEDs) (114).

Total number of comorbid somatic conditions

In the biological-biomedical domain, the total number of comorbid conditions had the strongest negative influence on all three quality of life measures. This is consistent with previous research that chronic illnesses contribute to poor quality of life (291). Previous research suggests that self-rated health status primarily reflects physical health (73) (i.e., limitations in physical functioning and chronic or acute conditions) and to a much less extent mental health problems (74).

My research however suggests a somewhat different pattern of association between comorbid somatic conditions and quality of life for PWE as comorbid somatic conditions were negatively associated with all three quality of life measures. In PWE comorbid somatic conditions have an impact on self-rated mental health status and overall life satisfaction. This is consistent with the recognition of a mind-body relationship between disease and quality of life that is consistent with the biopsychosocial model. Epilepsy has physical components (seizures) and psychological components (the impact of seizures on brain function leading to symptoms of anxiety and depression).

Comorbid conditions examined in this study such as asthma, diabetes, arthritis, hypertension, heart disease and stroke are also associated with physical and mental symptoms, such as physical limitations and pain which likely impact mental health and

function. The management of comorbid conditions raises questions about overlapping and discrete pathoetiology with mental health conditions (292). Both primary and secondary prevention, especially for cardiovascular and pulmonary conditions, may be beneficial for PWE since cardiac and respiratory mechanisms have been suggest in sudden unexplained death in epilepsy (293).

Number of family doctor/general practitioner visits in past 1 year

The number of family doctor/general practitioner visits in the past 1 year also supports a similar pattern, although the association was stronger for self-rated health status than self-rated mental health status. These findings likely reflect the type of care family doctors and primary care physicians typically provide to PWE (treatment of comorbid somatic conditions and disease). My findings suggest when asked about family doctor/general practitioner visits in the past PWE tend to think more in terms of their physical health. This is interesting in that the question specifically asks “In the past 12 months, how many times have you seen, or talked on the telephone, about your physical, emotional or mental health with a family doctor (pediatrician) or general practitioner?”

Psychological domain

Self-perceived life stress

Self-perceived life stress also had a consistent negative association with all three quality of life domains with the strongest negative association with life satisfaction. Previous research has suggested that fear of seizures, social stigma, unemployment, discrimination and lack of social support are stressors that contribute to depression in persons with epilepsy (99). The unpredictable nature of seizures is consistent with a form of chronic stress. While self-rated mental health status is a single-item measure my

findings are consistent with a recent cross-sectional study of 150 adult persons with epilepsy which found stress accounted for 39% of the variance in depression scores, as measured by the Beck Depression Inventory (147). In my study the largest influence of self-perceived life stress was on life satisfaction which suggests a more global influence on quality of life.

Mood and anxiety disorders

My findings provide further support the literature that poor mental health has the greatest impact on PWE. Numerous studies have found psychosocial factors and poor mental health - not clinical variables (i.e., age of onset, seizure frequency and side effects from anti-epileptic drugs) have the greatest impact on quality of life in PWE (2). This is evident in that PWE view their main handicaps as psychological rather than purely physical and complain about a lack of counseling and support (5).

The research also sheds light on the negative association between mood disorders and the three quality of life measures that were examined (self-rated health status, self-rated mental health status and life satisfaction). Presence of a mood disorder had a consistent negative association with all three quality of life measures. Presence of an anxiety disorder had a negative association with self-rated health status and self-rated mental health status but was not associated with life satisfaction.

Number of mental health professional visits in the past 1 year

The number of mental health professional visits in the past year was only associated with self-rated mental health status. This association provides support for the self-rated mental health question measuring mental health and not physical health or disability. It is important to note that no cause and effect can be attributed here – only an

association. It is consistent that people with poor mental health are more likely to be seeing a mental health professional for care. Further discussion of the implications of mental health professional visits is provided in discussion of the full biopsychosocial model.

Social domain

The social domain explained about the same amount of variance in quality of life as the biological-biomedical variables. In my analyses all of the social variables had a positive association on quality of life. This is consistent with previous research that examined the negative impact of epilepsy on the development of human capital (education, employment and income). Previous research has suggested the quality of life trajectory in epilepsy is modified by higher education and occupational attainment (199). These findings are consistent with previous research suggesting education, employment and income may help to improve health both directly and indirectly through work and economic conditions, psychosocial resources and a healthy lifestyle (198).

Education and annual household income

Population studies from the United States show persons with a history of epilepsy report lower educational attainment and lower household income compared to those without epilepsy (195). Education level was however only predictive of self-rated health status. This was consistent in the model looking only at the social domain as well in the analysis examining the full biopsychosocial model. Annual household income was statistically significant, but only mildly associated with all three quality of life measures.

Employment

Employment (working in the past 12 months) was also a significantly associated with self-rated health status and self-rated mental health status. Employment was also significantly associated with life satisfaction, although the association was half that of the other quality of life measures. People with active epilepsy (consistent with the case definition used in the CCHS) are more likely to be disabled and therefore not employed. This lower association could be the result of adjustment to long term disability status, especially in the case of childhood onset epilepsy. Persons with epilepsy, who have never been able to work, may place less emphasis on employment in their ratings of life satisfaction. Since the CCHS is not a longitudinal survey I am unable to test for such temporal effects.

Marital status

Marital status (married/common law) on the other hand was only significantly associated with life satisfaction. This would suggest that overall ratings of life satisfaction in PWE may be reflective of the quality and quantity of social support they receive and possibly the economic benefit that comes with marriage. When PWE evaluate life satisfaction it appears that they may be reflecting on the presence or absence of such a significant relationship. Marriage can also help people psychologically cope with economic or social problems when they occur (294). This has led scholars to propose a protection hypothesis for marriage based on improved social integration (greater social ties via connection to a larger social group and family) (295, 296). Marriage helps foster a sense of meaning, promotes healthy behaviors, reduces risk factors and enhances adherence to medical regimens (297, 298) through spousal

monitoring (299). Marital status differences in health may also be the result of an enhanced financial position that comes with marriage (294). Longitudinal research on PWE is needed to examine these theories in more detail.

Sense of belonging to the community

Sense of belonging to the community was also significantly associated with all the three quality of life variables. The strongest association was again with life satisfaction. The term sense of community has been defined as “an experience, generated within the interplay of individual and group, which engenders the perception of belonging and ameliorates feelings of isolation” (p. 195) (225). Sense of community is thought to have a beneficial effect on stress, decrease loneliness and engendering feelings of hope through the importance of affiliations with others (225). People with epilepsy are known to experience stigma around their disease. These feelings of stigma can lead to avoidance behaviors and social isolation. While the CCHS question assessing sense of belong to the community does not measure stigma directly, my findings do suggest a consistent association of better quality of life in PWE who feel more connected.

These findings are consistent with other examinations of sense of belonging to the community and self-rated health status which found a very strong sense of belonging to the community was significantly associated with very good or excellent self-rated health status (OR = 1.7, 95%CI: 1.6-1.9) and somewhat strong sense of belonging to the community (OR = 1.3, 95%CI: 1.2-1.4) (236). A recent investigation also found that persons with a stronger sense of belonging to the community and higher social support reported lower rates of depression (235). These findings help highlight the importance of

programs to help alleviate stigma as the stigma of epilepsy is universal “Everywhere in the world it is a hidden disease” (300).

Hypothesis 1.2. The full model that includes the biological-biomedical, psychological and social domains will explain quality of life in persons with epilepsy better than the biological-biomedical model alone.

I hypothesized the full model that includes the biological-biomedical, psychological and social domains would explain quality of life in persons with epilepsy better than the biological-biomedical model alone. My findings were consistent with this hypothesis.

Based on the whole set correlation analysis the biopsychosocial model does explain a greater percentage of the variance than the biological-biomedical model. As Galizio (1985) stated one of the problems with the biopsychosocial model: “at the present time such models can only identify factors or variables that can be demonstrated to be protective or to increase risk, but the relative variance accounted for by these various factors is largely unknown....it is not at all clear which variables account for the greatest amount of variance and which may be trivial” (p. 427) (131).

The whole set correlation technique (via standardized beta weights) also provided an expanded approach to understanding the variables that most explain the individual quality of life domains (self-rated mental health status, self-rated mental health status and life satisfaction). These findings for the full biopsychosocial model provide a more complete view beyond that was provided by the individual domains. The standardized beta weights, generated as part of the whole set correlation analysis, also shed light into the shared components between the three quality of life measures as well as the differences between the quality of life measures.

Full Biopsychosocial model

Biological-biomedical

The contribution of age to the individual quality of life measures was moderated except for the small positive influence on self-rated mental health status. Gender, while not significant across any of the quality of life measures in the biological-biomedical model, does demonstrate a small but significant contribution to quality of life in the overall model. However the positive effect is only seen in females with epilepsy. This is different than a recent study with data from the CCHS 1.1 which found no difference in subjective quality of life between females and males with epilepsy (301). The findings are however consistent with data from the 2001 and 2003 Medical Expenditure Panel Survey that examined differences in self-rated health status by gender in adults with diabetes. Women, despite being older, having more comorbid conditions, physical limitations and lower mental functioning status rated their health status higher than men (302).

The Institute of Medicine report *Exploring the Biological Contributions to Human Health: Does Sex Matter?* highlighted the importance of understanding gender differences at the societal level based on individual behaviors, lifestyle and surroundings (117). Overall, female gender is associated with slightly better quality of life once the other variables in the full model are controlled for.

In the final model, total number of comorbid somatic conditions remained significantly associated with poorer quality life across all three dependent variables. The standardized beta weights do favor a larger association with self-rated health status.

Previous research supports that persons with epilepsy have more comorbid somatic conditions than people without epilepsy (39, 118, 119).

At the present time it is not clear the cause of this differential. Previous research suggests socioeconomic deprivation (192-194, 38) may be one of the major associations. Persons in poor environments experience significantly higher amounts of stress, poor mental health (230, 231) and are more likely to adopt unhealthy coping behaviors such as smoking or drug/alcohol use (232). Furthermore, a lack of understanding among many health professionals and sports instructors about epilepsy has led to unnecessary restriction of physical activity in the past (303). Less than half of patients had ever talked to their doctor about physical activity (303). In addition overprotection (by family members), understimulation, low self-esteem, isolation, depression and anxiety are significant barriers to a healthy lifestyle (304) that is important for the prevention of chronic diseases.

In the full biopsychosocial model, the number of family doctor/general practitioner visits in the last 1 year was associated with self-rated health status only. The association with self-rated mental health status found in the biological-biomedical only model was not present in the full model. The skewed nature of this data however makes it difficult to assess the association of medical care on quality of life.

Psychological

In the psychological domain, the negative association between self-perceived life stress and all three dependent variables remained significant. The strength of this association was slightly improved in the final model providing support for the overall negative impact of chronic life stress on quality of life. The association was strongest on

self-rated mental health and life satisfaction. The current research supports the PWE report that stress increases the frequency of their seizures (141, 144) with 30% identifying stress as a precipitant of their seizures (145).

The presence of a mood disorder also remained significantly associated across all three dependent variables. The strength of this association was somewhat moderated in the full model versus the psychological model only. More specifically this reduction was seen in self-rated health status and life satisfaction, but less so for self-rated mental health status. In PWE the strong association of mood disorders and quality of life is a critical consideration for the treatment of whole person. These effects are particularly pressing for epileptologists as they are most likely treating persons with more treatment resistant epilepsy.

Estimates of lifetime prevalence of depression in PWE range from 29% in population based studies to 50% in tertiary referral centers (150). This contrasts with lifetime prevalence rates of depression estimates in the general population of 16 to 22% (151, 152). Furthermore, PWE with depression have significantly more medical and psychiatric visits (153). Screening and proper treatment is not only important for quality of life but it may have an impact on targeted use of health services.

The association of anxiety disorders with self-rated health status was moderated in the full biopsychosocial model. A moderation effect was also present in ratings of self-rated mental health status - the standardized beta weight was small but still significant. Anxiety disorders and mood disorders are frequently comorbid. Again the seriousness of anxiety disorders is most likely encountered in patients treated at tertiary centers. PWE reported lifetime anxiety of 30% versus 19% in the general population,

while anxiety in the last year was 25% for PWE versus 12% in the general population (164). The unpredictable nature of seizures is often a source of ongoing stress and anxiety for PWE.

The negative association between the number of mental health professional visits (social worker/counselor and/or psychologist) in the past 1 year remained significant in the full biopsychosocial model. This association remained relatively unchanged in the full model. The association remained limited to self-rated mental health status. This provides additional reliability and validity that the self-rated mental health status question in the CCHS is a reasonably domain specific quality of life measure related to psychological well-being.

Despite strong epidemiological and clinical evidence that PWE suffer disproportionately with mental health diagnoses, a large proportion of PWE remain unscreened and untreated for depression and other mental health conditions (7, 8, 11). Neurologists unfortunately continue to focus primarily on the control of seizures (6).

Social

The social variables have their own relationship with quality of life and thus should be considered by clinicians who focus on the biological-biomedical components of epilepsy treatment. A recent survey of epileptologists, neurologists and professionals in epilepsy care found a lack of awareness about social services as the most commonly identified management barrier to optimal epilepsy care (305).

Many of the social variables remained significant in the full biopsychosocial model. The associations were moderated but remained significant. Education slightly increased in strength, while annual household income and employment decreased

slightly. The strength of association for the married/common-law variable increased slightly. This is consistent with the conceptual view of life satisfaction, in that people evaluate the tangible aspects of their lives while weighing the good against the bad to determine a judgment of overall satisfaction (84).

A majority of PWE are in fact capable of full participation in the labor market. However research has found PWE have consistently higher levels of unemployment compared to the general population (19, 306-308) and when employed are more likely to be working in unskilled and manual jobs. PWE are also more likely to be underemployed (308). Helping PWE overcome employment barriers is critical as one survey found many PWE feel the experience of being refused a job or having been unemployed as a declaration of incompetence (309).

Worldwide, persons with epilepsy are known to have significant difficulties obtaining and maintaining employment (197, 308, 310-313). Outside the U.S. employers still report significant concerns over hiring someone with epilepsy (314). In the U.S., the Americans with Disabilities Act of 1990 (ADA) provided more sweeping legislation against discrimination in employment settings (315). However inclusion of epilepsy had to be further clarified in a 2008 amendment that ensures the law covers impairments, such as epilepsy, that are episodic in nature or in remission and that substantially limit a major life activity when active (18).

Sense of belonging to the community also remained significant, but was also moderated in the final model. The association between stigma and epilepsy reaches back thousands of years. In Greek; Epilepsy means the “sacred disease”. The mystical nature of epilepsy is also evident in its frequency of mention in the religious texts such as the

Bible. Epilepsy continues to be shrouded in misinformation (316). The history of epilepsy has been summarized by one writer as “4,000 years of ignorance, superstition and stigma followed by 100 years of knowledge, superstition and stigma” (317). Throughout history persons with epilepsy have been stigmatized by misperceptions such as being possessed by evil spirits. In developing countries epilepsy is often thought to be infectious (318).

Improving connection to the community may be one way to address felt stigma from the perspective of the PWE but it may also impact misperceptions among the general population. As ADA sponsor Tony Coelho (2006) noted “The cloud grows darker each time the media - news or entertainment - portrays epilepsy in a way that highlights myths, misconceptions, and misunderstanding. The stigma has been very stubborn and pervasive for hundreds, if not thousands, of years. But, there is hope” (p 3) (319). While education level is negatively correlated with the perception of stigma (320) ending the stigma of epilepsy may reside in reaching the young while they are still forming their values and societal attitudes (319).

Educational campaigns in community settings, work sites, schools, churches and stores have been suggested as a method to improve general population knowledge (321). Social marketing approaches include protesting inaccurate depictions of PWE in the media, education of PWE and key social groups and increasing the public’s contact with PWE (322, 323). Such methods must balance the message that PWE are “no different that you and me” with “they are different and deserve special treatment” (322).

Hypothesis 1.3. Individually, the psychological and social domains will explain quality of life better than biological-biomedical model.

The whole set correlation findings indicate the psychological variables explained more of the variance in quality of life than the biological-biomedical model alone. The whole set correlation findings also suggest the social domain is at least equivalent to the biological-biomedical domain in explaining the variance in quality of life PWE.

The partialling technique in set correlation provides further evidence of the strength of each domain when the influences of the other domains are controlled for. In particular, the psychological and social domains provide a better explanation of quality of life in PWE than the biological-biomedical domain only. These changes in the multiple R^2 by partialling are consistent with Baron and Kenny (1986) definition of a *moderator* (238).

When controlling for the influence of the other domains (psychological and social), the explained variance of the biological-biomedical dropped more dramatically from the whole set correlation results when the psychological and social were controlled for. The explained variance of the psychological domain was moderated the least when controlling for the influence of the other domains (biological-biomedical and social). This provides additional support for the importance of the psychological dimension and quality of life in PWE.

The explained variance of the social domain was also moderated when controlling for the influence of the other domains (biological-biomedical and psychological). Social factors such as education, income, employment status, marital status and sense of belonging to the community are not always the result of epilepsy, but are often a “side-

effect” of epilepsy. The less dramatic drop in explained variance in the social domain also provides support for the importance of the social dimension relative to the biological-biomedical dimension with regards to quality of life in PWE.

Research question 2. Does use of mental health services (social workers/counselors and psychologists) have a moderating effect on quality of life in PWE?

Hypothesis 2.1. Use of mental health services (social workers/counselors and psychologists) will explain additional variance in quality of life for PWE.

In terms of my Research Question 2 my findings are less compelling. As part of the analyses the psychological domain was tested without the number of mental health professional visits variable and with the variable. The addition of the number of mental health professional visits in past 1 year variable only contributed an additional 1% to the multiple R^2 . The mental health visits variable had a large positive skew. A decision was made not to conduct log transformation as this would not fully address the skew. In addition, log transformation makes interpretation less parsimonious. Since cross-sectional data is not able to assess improvement from treatment it was more straightforward to include the variable without transforming it.

There are some potential explanations for the minimal influence of mental health services use on quality of life in my study. These include lack of screening and referral for mental health services that are provided by social workers and psychologists. Gilliam et al. found that 82% of neurologists in their survey do not routinely screen PWE for depression (167). A more recent survey of epileptologists found 62% of our respondents did not routinely screen for depression and 42% did not feel comfortable initiating treatment for depression (11).

Despite the extensive population and clinical research establishing the impact of poor mental health on PWE, previous studies found 38% of patients with major depressive disorder were never referred for treatment and 68% of those with minor depression were untreated (7). Another study found that only 35% of 60 patients with symptomatic depression for >1 year were offered treatment within the first 6 months of symptom onset (8). This problem has also been established in Canadian research. Population research from Canada found 38% of depressed PWE had no consultations with a mental health professional in the past year (42) despite universal insurance coverage for mental health services in Canada (80). One recent qualitative study suggested that epilepsy-related social services may be under-utilized due to a lack of awareness (324).

Previous research found PWE with depression have significantly greater medical and psychiatric visits (153), higher levels of perceived seizure severity and poorer seizure recovery than those without depression (154). In one study depressed PWE had a 135% increased likelihood of hospitalization than PWE not depressed. This was 3.7 times higher than other comorbid conditions (325). In addition, poor quality of life is associated with greater utilization of medical resources (number of clinic visits, emergency room visits and in-patient admissions) (169). Previous research has found that delays in psychiatric consultations in the non-epilepsy population leads to longer length of hospital stay, this was evident even after controlling for medical conditions, psychiatric reason for referral and diagnosis and the interventions recommended (326).

The need to integrate psychological and social services into epilepsy care

The 2012 Institute of Medicine (IOM) report *Epilepsy Across the Spectrum: Promoting Health and Understanding* continues to highlight the dominant biological-biomedical view of epilepsy: “Improving the lives of people with epilepsy and their families, to a large extent, begins with access to high-quality, patient-centered health care that facilitates accurate diagnosis and effective treatments and management” (p. 5) (18).

However, physicians express doubts about their success in patient education and tend to be pessimistic about their ability to influence their patients’ lifestyles (327, 328). In one study neurologists rank among the least likely to provide prevention-related counseling or screening to their patients (329).

A recent study by Gilliam and colleagues (2009), epilepsy patients’ clinical interviews with neurologists averaged 11.8 minutes (range 2.1-39.9, sd = 6.5). Only four percent of a 12-minute visit was spent on quality of life and activities of daily living (less than half a minute). The majority of the visit discussion was focused on medications, comorbidities, seizures/symptoms, tests/results and side effects (330). A follow up study found use of a pre-visit assessment tool on discussions of epilepsy increased the number of discussions about adverse effects and mood/behavioral issues (331). Follow up research found 50% of neurologists reported continuing to use the tool in everyday practice with patients with epilepsy 10 months after the intervention. This would suggest the epileptologists practice behaviors can be modified.

My research further examined the biopsychosocial model and quality of life in PWE consistent with the recognition that epilepsy is more than seizure frequency and severity:

“Epilepsy is much more than seizures. For people with epilepsy, the disorder is often defined in more everyday terms, such as challenges in school, uncertainties about social and employment situations, limitations on driving a car, and questions about independent living” (p. 192) (18).

The IOM has also called for what they call a “whole-patient perspective” for PWE:

“that provides people with epilepsy, their families, and caregivers with a coordinated, individual-specific approach to health care, mental health care, educational opportunities, and community services and promotes optimal self-management and quality of life” (p. 30) (18).

In light of the recent IOM report it is especially important to consider an expanded role of social workers and psychologists in the care of PWE. Such roles should go beyond screening, discharge planning and referral by moving social workers and psychologists more towards agents of change roles in the healthcare system (332).

In the tertiary care setting the potential impact of integrated social services has received little attention, despite guidelines from the National Association of Epilepsy Centers (NAEC) that call for the necessity of including social workers and psychologists as part of the “interdisciplinary care team approach” to care in level 3 epilepsy centers (27). According to NAEC report *Essential services, personnel, and facilities in specialized epilepsy centers – Revised 2010 guidelines*, Level 3 and 4 centers are expected to “provide the basic range of medical, neuropsychological and psychosocial diagnostic and treatment services needed to treat patients with refractory epilepsy” (p. 2326) (27). These guidelines call for a social worker (ACSW preferred) experienced with coordinating case services for outpatient PWE. The guidelines indicate preference for a clinical psychologist/counseling psychologist with a PhD from an American Psychological Association (APA) approved program and a special interest in epilepsy (27).

Despite these recommendations most medical-based tertiary epilepsy centers in North America do not provide comprehensive intervention programs that address the psychosocial, educational, vocational and family support needs of persons with epilepsy (PWE) and their families (35). Furthermore, these guidelines were formulated by physicians with limited expertise of the psychological and social dimensions to health. This disparity also points to the limited ability of the current United States healthcare system in addressing these issues as the reimbursement system is primarily financially driven towards quantity of care over quality of care.

While the goal of “no seizure and no side effects” is thought to be achievable and expected, there is a demand from the purchasers of health care services that this goal be achieved more efficiently and at a lower cost - while also improving quality of life (27). Incorporating social workers and psychologists into treating the “whole patient” is consistent with the skills and abilities of clinicians in both fields. Social workers have unique skill sets with regards to mental health screening and treatment that are not provided by medically-focused nursing care, especially in area of discharge planning (333). Social workers are also critical through their training in the biopsychosocial model in terms of providing psychoeducation and life-style counseling (334). Patient education via social workers has been shown to be effective for improving health outcomes such as reduced medication needs, reduced duration of treatment and hospital stays, improvements in risk-reducing behavior, and reduction of risk factors (335).

As pay for performance measures are quickly moving forward in the health care system, the recent American Academy of Neurology (AAN) report *Quality improvement in neurology: AAN epilepsy quality measures* failed to go beyond the strictly biological-

biomedical approach (336) called for by the IOM. With the current trend towards cost containment in health care it is less likely that Level 3 and 4 Comprehensive Epilepsy Centers see the value in adding social workers or psychologists to their interdisciplinary teams versus viewing them as just ancillary staff as has been noted in previous studies in the hospital setting (337).

However a recent study examining the value of social workers in hospice care found increased social work involvement was significantly associated with lower hospice costs. In addition, the research found better team functioning, reduced medical services (fewer nights of continuous care and lower number of hospitalizations), fewer visits by other team members as well as increased client satisfaction (338).

These findings suggest other psychotherapeutic interventions provided by social workers and psychologists may also impact the delivery of targeted care and reduce the costs of undiagnosed or under-treated psychosocial issues (339, 340). Interestingly, the research on psychotherapeutic interventions has come primarily from the medical journals. The biological, psychological and social effect of these previous interventions merits further discussion, especially the evidence that such treatment have biological effects on the brain.

Potential psychotherapeutic interventions for PWE

Cognitive Behavioral Therapy (CBT)

By far the most studied psychotherapy in epilepsy has been CBT. In cases of depression and panic, CBT produces superior long-term persistence of effects, with relapse rates half those of pharmacotherapy (341-343). CBT also reduces the risk for subsequent symptoms following treatment termination for depression and the anxiety

disorders (343). Despite a handful of published articles, all previous investigations of CBT in PWE have involved very small sample sizes ($n < 30$). In addition, these studies have focused exclusively on group CBT. No studies have specifically examined individual CBT in PWE, or the effects of individual psychotherapy on quality of life despite such recommendations (175-178).

Current evidence from neuroimaging studies in the non-epilepsy population further suggest that CBT targets areas of the brain noted to be dysfunctional in PWE. A recent systematic review of 34 relevant neuroimaging articles was conducted on temporal lobe epilepsy (with and without depression), depression (with and without epilepsy), and CBT and antidepressants (344). Results of positron emission computed tomography (PET), functional magnetic resonance imaging (fMRI), single emission computed tomography (SPECT), or proton spectroscopic imaging (H-MRSI) studies indicated hypoactivity in the frontal cortex and hippocampus; and hyperactivity in the left dorsomedial prefrontal cortex for depression (with and without epilepsy). Hypoactivity was consistently found in the frontal cortex and temporal region in temporal lobe epilepsy (with and without depression). Studies of non-epilepsy groups suggest that CBT targets the frontal cortex, prefrontal cortex, temporal lobe, thalamus and hippocampus. All of these areas are dysfunctional in temporal lobe epilepsy with depression. Overall these findings suggest a beneficial biological effect of psychotherapy.

While CBT is highly effective for treating depression there are concerns about dropout rates which range between 18% and 36% in one meta-analysis (345). It is hypothesized that identifying the client's deficits in thinking work to rupture the therapeutic alliance (346, 347) causing termination of CBT (348-350). CBT approaches

alone may be unsuccessful for certain “unsolvable” problems common in the epilepsy population (i.e., lack of driving privileges). Over the years these concerns have moved CBT towards a more strengths-based approach. This relatively “new” field has been termed positive psychology. Positive psychology offers secondary control over “unsolvable” problems by focusing on exercising one’s reactions to such events or situations (351). These approaches may work to reduce premature termination and improve adherence to the interventional program.

Positive Psychology

As an outgrowth of CBT, positive psychology focuses on building positive emotions, character strengths, and meaning in addition to challenging negative emotions (352). Since 2006, the field of positive psychology, has made significant gains in analyzing the benefits of these targets (353-357). Rather than dichotomizing well-being into negative or positive, positive psychology recognizes a continuum between the negative and positive (358). The therapeutic approach is concerned simultaneously with the relief of suffering and the promotion of well-being (358).

Lopez and Snyder (2003) in their book *Positive Psychology Assessment* recommend broadening Axis IV within the DSM-IV system to reflect psychosocial/environmental resources. These include attachment/love/nurturing with primary support group, connectedness/empathetic relationships/humor filled interactions, accessible educational opportunities and support, meaningful work/career satisfaction/self-efficacy, safe housing with elements that foster health development, financial resources adequate to meet basic needs and beyond and access to high

quality/reliable health care services (191) all of which are within the purview of social work (359). Many of these variables were assessed as part of my research.

Positive psychology approaches are also consistent with Bandura's self efficacy theory in that setting goals and monitoring success will help improve client's perceived self-efficacy (351). An improved sense of self-efficacy or beliefs in one's capabilities to organize and execute action to produce attainments, can assist the PWE toward coping with their psychosocial difficulties (360). Self-efficacy approaches reduce disability and increase emotional wellbeing (361). Such applications of neuropsychological and psychosocial interventions as treatment for epilepsy may also improve a person's quality of life (362).

This integration of CBT and positive psychology has been termed quality of life therapy (QOLT) (363). The QOLT approach is viewed as a comprehensive positive psychology approach to relapse prevention that functions within the cognitive therapy model. Frisch defines the use of positive psychology in QOLT as "the study and promotion of human happiness, strengths and a better quality of life for all" (p. 5) (363). The focus is on happiness and life satisfaction over other positive affects because these constructs are associated with fulfillment and accomplishment of personal goals in areas of life that individuals value (363). At present no research integrating CBT, positive psychology or the strengths-based approach from the field of social work has been conducted in PWE. Social workers and psychologist are critical to the planning, implementation and research leading to evidenced-based practices.

Future research

My findings support a need for further research into quality of life for PWE. The most impact may come from longitudinal research that is able to untangle the temporal influence of epilepsy on quality of life. Such studies have been all but non-existent in the fields of social work and psychology. Therefore the perspective of social scientists in these areas has been extremely limited. The field of social work considers the biopsychosocial perspective a foundation of social work theory and practice (130).

While the population perspective of this research and the work of others have been informative to practitioners, researchers and policy makers, there is a need to conduct more inductive research on quality of life in PWE. The current literature is sparse in terms of qualitative investigations (324, 364-368). In-depth qualitative interviews of PWE would provide a rich description of their experiences with regards to the biopsychosocial model and quality of life. Such research would inform both clinical and population based research. Qualitative research would also be informative to investigators planning interventional research for PWE.

Future research in social work should focus on an interprofessional approach. This approach is further bolstered when considering the strong evidence that biological processes such as neuroplasticity are influenced by psychological and social experiences that drive the development of new neural pathways (130). Research also supports the impact of talk-therapy interventions on the immune system and the body's ability to combat disease (viruses, HIV, cancer, autoimmune diseases) as well as wound healing (369). Therefore the development of translational research with researchers in the

neurosciences and immunology may lead to further validation of the influence that social workers and psychologists can have on the biological aspects of health and disease.

Interprofessional investigations should consider use of a comparative effectiveness methodology. This method would allow testing of the current standard of care (seizures and medication management) versus a biopsychosocial based intervention that adds psychosocial components to patient care. Investigations from this perspective have been able to show the effectiveness of CBT over medications for insomnia (370). In epilepsy care, comparative effectiveness research has primarily focused on comparing medical regimens to surgical intervention (371) or differences between AED regimes (372).

The issues and concerns identified in my research and the work of others would also benefit from greater funding from federal agencies. However epilepsy research is not funded at the level it should be. Meador and colleagues (2011) found that epilepsy (when adjusted for prevalence) receives significantly less funding from the National Institutes of Health than other neurological disorders. For example, funding for research on stroke is 1.7 times higher and amyotrophic lateral sclerosis is 61.1 times higher than epilepsy. In addition most research on epilepsy has focused on suppressing seizures rather than curing the disorder (373). Potential reasons for this disparity offered include: 1) a consistently poorer quality of epilepsy grant proposals, 2) inequality of representation and expertise on epilepsy among NIH panels, 3) allocation of Congressional funding, 4) more effective lobbies that promote research funding for other neurological diseases and 5) a poorer and more disadvantaged population (373).

Limitations

The CCHS has significant limitations. The CCHS is a cross-sectional study and this greatly limits the ability to assess any casual or temporal relationships between epilepsy, mental health diagnoses, mental health services use and quality of life. Homes without telephones or individuals with only cellular phones were excluded from the survey. The CCHS also excludes institutionalized individuals such as those who live in group homes, nursing homes or prisons as well as the homeless. In the Canadian health system institutionalization is reserved for persons with severe and multiple cognitive, physical or developmental issues (41). While the prevalence of epilepsy in persons with mental retardation has been reported around 20% (374) overall, this constitutes a very small proportion of the overall population with epilepsy. These factors may limit the number of respondents who are elderly and those with chronic epilepsy and mental illnesses.

Since no confirmation is made by health professionals self-report of epilepsy by participants is also limited. Therefore, respondents may over or under report their epilepsy. Persons may also report non-epileptic spells as epilepsy. Between 10 and 58% of adults referred to epilepsy centers turn out to have non-epileptic events (375). Self-reports are also subject to recall bias and social desirability bias. For example, height and weight in the CCHS were found to be higher for height and lower for weight on self report, leading to lower BMI estimates than physical measurements (376).

The case definition of epilepsy in the CCHS also does not allow for specific examination of persons with intractable epilepsy, the length of time with a diagnosis of epilepsy, seizure type or number/type of AEDs used. Epilepsy-specific content in the

currently available epidemiological surveys (BRFSS, CHIS) have been limited to epilepsy diagnosis, frequency of seizures in the past year, use of medication, and visits to a neurologist in the past year. So these surveys like the CCHS are also unable to ascertain individual epilepsy syndromes, seizure type, seizure severity and etiology (18).

There were a limited number of variables in the biological-biomedical domain which may limit the potential for more explained variance in quality of life. The biological-biomedical domain may have been strengthened by data on medication use for epilepsy. For example class of AEDs used by respondents may impact quality of life in terms of self-rated mental health status. Valproic acid, carbamazepine, oxcarbazepine and lamotrigine are approved by the United States Food and Drug Administration as mood stabilizers. Also data on seizure type and number of seizures may enhance the explained variance in quality of life in PWE. In terms of health care utilization the explained variance in quality of life may be influenced by use of specialist medical care such as visits with a general neurologist or an epileptologist. These variables were not collected as part of the CCHS.

Data from the Behavioral Risk Factor Surveillance System, a population survey in the United States, have suggested seizures in the past 3 months OR = 1.12 (95%CI: 0.56-2.25), and current use of medication for epilepsy OR = 0.58 (95%CI: 0.30-1.10) do not explain number of poor mental health days per month as much as social/emotional support OR = 3.22 (95%CI: 1.84-5.61) and daily limitations (normal activities like working, school, or socializing with family or friends) due to epilepsy and its treatment OR = 3.05 (95%CI: 1.41-6.58) (377). This would suggest addition of such questions to the CCHS would not contribute that dramatically to the explained variance in quality of

life by the biological-biomedical domain or the full model. However the inclusion of such data would strengthen the case for the biopsychosocial model over the biological-biomedical model in the current research.

Persons with more severe epilepsy are more likely to be stigmatized and feel more socially isolated by their epilepsy than those whose seizures are well controlled. Therefore, people are also less likely to disclose sensitive information in interviewer administered surveys than in self-administered surveys (378). It has been suggested at least 10% of people with epilepsy will not disclose the diagnosis in door-to-door or telephone surveys (21). Other investigations have found up to 15% of PWE did not disclose their diagnosis to general practitioner (379). In addition, the term "seizure disorder" is not used in the case definition. Since this is a frequently used euphemism for epilepsy the CCHS may miss individuals who believe they have a "seizure disorder" and not epilepsy - even though they are in fact the same diagnosis.

While self-report chronic medical conditions are valid when compared to professional assessments (380, 381), the comorbid conditions and mental health diagnoses in the CCHS are also not verified by a health professional. Comorbid conditions are also not defined by sub-categories (i.e., diabetes type) (382). Mental health diagnoses are also lumped together into two large groups (mood disorders and anxiety disorders). Respondents are provided a list of the diagnoses in these two groups in order to answer the question. The stigmatizing nature of mental health diagnoses may also impact responses. In terms of mental health services use, no information is available to determine what type of medical or psychotherapy treatment persons received or how long they have received mental health treatment.

Response rates to general population surveys (especially those conducted by telephone) have declined significantly over the past several decades leading to increase in non-response bias. For example for the BRFSS, the median participation rate was 71.4% in 1993, 48.9% in 2000 and 51.1% in 2005 (383). Some reasons for this may be due to over surveying of population, the rise of telemarketing (leading do-not-call registries that limit participation in research surveys even though they do not fall under the do-not-call rules), increasing demand, length and sophistication of surveys, the greater use of cell phones and longer working hours of the Americans which limit access to participants (383). In comparison the CCHS has a high participation rate (85%) compared to these trends in the United States.

Due to the population-based nature of this study this study relied heavily on single-item measures of quality of life (self-rated health status, self-rated mental health status and life satisfaction), self-perceived life stress and connection to the community. A single-item assessment of self-rated mental health has limitations. In the CCHS 1.2 the sizeable percentage of respondents classified as having a mental illness, who did not perceive their mental health as poor, may be the result of misclassification, lower severity of symptoms, lower morbidity burden, and lack of insight into morbidity, successful treatment or recovery. The small proportion of respondents without mental illness who self-reported their mental health as fair/poor suggests the self-rated mental health questions may be capturing sub-threshold symptoms or the fact that other factors other than mental health diagnoses influence self-perceived mental health (76). Since the concept “local community” is not defined in the sense of belonging to the community variable it may be understood and interpreted differently by respondents (236).

Single-item questions are used in surveys and are on the U.S. Institute of Medicine's list of eight national health outcome indicators (384). The trade off for single-item measures depends on the outcome of interest since these items offer "detail at the cost of respondent burden" but also "simplicity at cost of detail" (p. 584) (385). While single-item measures frequently perform as well as multi-item assessments, they may lack clarity over the definitions of the end points of scales (385). For example, people may interpret the term "best imaginable health state" as either the best they could be in their present situation or it could represent their health when they were young and fit (385).

Single-item measures may also be more sensitive than multi-items scales to the contextual effects of the preceding questions. For example, if self-rated health status is preceded by a series of questions about depression it may result in a more negative evaluation than if the question followed a section on well-being (384). In the CCHS, the first module of the survey asks five questions about satisfaction with the healthcare system. After this is a section on general health in which the 1st question is self-rated health status, the 3rd life satisfaction, the 4th self-rated mental health status, the 5th self-perceived life stress and the 8th connection to the community. From this perspective these questions are not structured to follow questions about health issues, conditions, disability or health behaviors that could negatively influence the respondent's ratings.

There is also limited generalizability of the current research to the U.S. population. While geographically close, the Canadian population is more homogeneous with over 85% of being Caucasian. The Canadian health care system is also significantly different than the United States. The findings of my research are however consistent with

findings from the around the world suggesting psychological issues (stress, the prevalence of mood and anxiety disorders) and social issues (limited education, income, employment and marital status as well as greater social isolation) are common in PWE.

Conclusions

This study is an important step in understanding quality of life in epilepsy from a population perspective. The findings of my study support both previous research and calls from professionals in the field of the importance of treating the whole person – not their seizures alone. My research supports a whole person approach consistent with the biopsychosocial model. In addition, the exploratory aspects of whole set correlation provide depth to our understanding of self-rated health status, self-rated mental health status and life satisfaction especially with regards to comorbid somatic conditions, use of primary care services, self-perceived life stress, mood disorders as well as employment, marital status and connection to the community. The partial set correlation findings suggest the psychological domain has the strongest influence on quality life once the biological-biomedical and social domains are controlled for.

Despite a long recognized need in the field of the importance of the psychological social factors in PWE there is still a paucity of research in the fields of psychology and social work. Social workers provide a vital understanding of the individual in their environment. In addition social work and psychology experts have provided a wealth of evidence-based practice approaches that are appropriate for the needs of PWE. Such information may also help the medical field move closer to truly integrating social workers and psychologists into the care of PWE. More equitable funding from federal agencies will be an important step to study new interventions. Social workers and

psychologists have every right to be at the table discussing the needs of PWE. Our perspective of health, wellness and evidence-based care has much to offer the field of epilepsy. Future research should focus on interprofessional approaches where the outcomes are defined by physicians and social scientists.

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