INVESTIGATING HEALTH RELATED QUALITY OF LIFE IN PEOPLE WITH SCHIZOPHRENIA

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INVESTIGATING HEALTH RELATED QUALITY OF LIFE IN PEOPLE WITH SCHIZOPHRENIA

Schizophrenia is a serious mental illness that significantly lessens health-related quality of life (HRQoL). A better understanding of HRQoL is needed to inform holistic and patient-centered treatments for schizophrenia. The purpose of this dissertation is to conduct an in-depth exploration of HRQoL in people with schizophrenia. The dissertation includes three components. The first component is an integrative literature review aimed at identifying factors associated with physical quality of life (QoL) in people with schizophrenia. The review reveals that symptoms of schizophrenia, depression, obesity or body mass index, and physical activity are associated with physical QoL in this population. The second and third components are based on illness narratives of 20 people with schizophrenia who had participated in a larger study of individuals diagnosed with serious mental illness. The second component of the dissertation is a qualitative descriptive study conducted to describe common HRQoL concerns in people with schizophrenia. The results indicate that these concerns were related to social relationships, psychiatric symptoms, psychiatric care, and employment. The third component of the dissertation is a parallel convergent mixed-methods study conducted to explore whether computerized lexical analysis (CLA) of illness narratives of people with schizophrenia can reveal their HRQoL concerns. CLA is an automatized process that counts words in text data and sorts them into pre-defined word categories. The results provide preliminary support for the potential use of CLA to efficiently assess HRQoL in people with schizophrenia as the CLA identified some of the HRQoL concerns that had been identified in the prior qualitative descriptive study. The results of the three studies reveal the complexity of the phenomenon of HRQoL in people with schizophrenia and can inform the development of strategies to identify and promote HRQoL in this population.

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LIST OF ABBREVIATIONS

Abbreviation	**Term**
CLA	Computerized Lexical Analysis
CLASP	Cognition, Language, and Affect in Serious Psychopathology Laboratory
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders 4th Edition
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders 4th Edition Text Revision
DSM-V	Diagnostic and Statistical Manual of Mental Disorders 5th Edition
HRQoL	Health-Related Quality of Life
IPII	Indiana Psychiatric Illness Interview survey
LIWC	Lexical Inquiry Word Count
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QoL	Quality of Life
WHO	Word Health Organization

CHAPTER 1

Introduction

Chapter 1 serves as an introduction to the dissertation research. The purpose of this dissertation was to conduct an in-depth exploration of health-related quality of life (HRQoL) in people with schizophrenia. The dissertation includes three studies on this topic. This chapter includes definitions of key concepts, a discussion of the significance and background of the topic, a summary of relevant theories, the purpose and specific aims of the dissertation, a description of the methods used in each study, and an overview of Chapters 2 to 5.

Concepts and Definitions

The following terms and definitions describe the major concepts addressed in the dissertation. Terms related to the substantive content of the three studies (i.e., schizophrenia and quality of life (QoL)) are described in Table 1.1. Terms related to the methods used in the dissertation are described in Table 1.2.

Table 1.1
Terms and Definitions Related to the Substantive Focus of the Study

Terms	**Definitions**
Cognitive Symptoms	Along with positive and negative symptoms, one of the major groupings of symptoms experienced by a person with schizophrenia. Includes changes in memory or other aspects of thinking, poor executive functioning (i.e., the ability to understand information and use it to make decisions), trouble focusing or paying attention, and problems with working memory (i.e., the ability to use information immediately after learning it) (National Institute of Mental Health (NIMH, 2016)
Concern	Matter of importance or a worried feeling (Online Cambridge Dictionary)
DSM-V	A manual for the standard classification of mental disorders used throughout the United States
Health-Related Quality of Life	Multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning; focuses on the

Terms	Definitions
	impact health status has on quality of life (Healthy People 2020, 2016)
Negative symptoms	Along with cognitive and positive symptoms, one of the major groupings of symptoms in people with schizophrenia. Includes disruptions to normal emotions and behaviors such as flat affect (i.e., reduced expression of emotions via facial expression or voice tone), reduced feelings of pleasure in everyday life, difficulty beginning and sustaining activities, and reduced speech (NIMH, 2016)
Physical QoL	Subset of QoL that includes a person's evaluation of their general physical health, their level of physical functioning, the bodily pain they experience, and their work limitations due to their physical health (WHOQOL Group, 1998; SF-36; Ware et al., 1993)
Positive symptoms	Along with cognitive and negative symptoms, one of the major groups of symptoms in people with schizophrenia. Includes psychotic behaviors reflecting a loss of touch with reality such as hallucinations, delusions, and disorganized thinking (NIMH, 2016)
Quality of life	Subjective evaluation of both positive and negative aspects of life (CDC, 2016).
Schizophrenia	Psychiatric disorder characterized by distortions in thinking, perception, emotions, language, sense of self and behavior. A diagnosis of schizophrenia requires two of the following symptoms: delusions, hallucinations, disorganized speech, disorganized or catatonic behavior, and negative symptoms. At least one of the symptoms must be delusions, hallucinations, or disorganized speech (American Psychiatric Association, 2013)

Table 1.2
Terms and Definitions Related to the Methods of the Study

Terms	Definitions
Computerized Lexical Analysis	Text-analysis software that systematically counts words in text data and sorts them into pre-defined word categories (Junghaenel, Smyth & Santner, 2008).
Content Analysis	Research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns (Hsieh & Shannon, 2005)
Mixed Methods	Research in which the investigator collects and analyzes data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or program of inquiry (Teddlie & Tashakkori, 2006)
Qualitative Description	Low interpretive inductive analysis that provides a coherent and useful summary of events in everyday words (Sandelowski, 2000)

Terms	Definitions
Quantifying or Quantitizing	Numerical transformations of narrative data to provide additional meaning to a set of findings (Boyatzis, 1998; Sandelowski, 2001; Tashakkori & Teddlie, 1998)
Integrative Review	Review conducted to infer generalizations about substantive issues from a set of studies directly bearing on those issues (Ganong, 1987)

Background and Significance

Schizophrenia

Schizophrenia is characterized by distortions in thinking, perception, emotions, language, sense of self and behavior. The Diagnostic and Statistical Manual-V (DSM-V) specifies that a diagnosis of schizophrenia requires two of the following symptoms: delusions, hallucinations, disorganized speech, disorganized or catatonic behavior, and negative symptoms. At least one of the symptoms must be delusions, hallucinations, or disorganized speech (American Psychiatric Association [APA], 2013).

Between 0.5% and 1% of the world's population (Word Health Organization [WHO], 2016; Centers for Disease Control and Prevention [CDC], 2016), and about 1.1% of the U.S adult population (3.5 million people) are diagnosed with schizophrenia (National Institute of Mental Health [NIMH], 2015). Based on NIMH (2015) estimates, out of the 4,947,915 people living in Indiana, 54,427 experience schizophrenia. Schizophrenia is more common in males than females (WHO, 2016). Men typically experience the first episode of the illness at about 21 years of age, and women experience the first episode at about 27 years of age (CDC, 2016).

People with schizophrenia have a high rate of physical and psychological comorbidities that shorten their life expectancy by 15 to 20% (Barnes, Murphy, Fowler & Rempfer, 2012; Foldemo et al., 2014; WHO, 2016). Poor diet, sedentary life style, and medication side effects in people with schizophrenia increase the risk for physical comorbidities compared to the general population (Muir-Cochrane et al., 2008). People with schizophrenia are three times more likely to die of cardiovascular disease (Muir-Cochrane, Cleary, Walter & Matheson, 2008) and have higher rates of stroke, diabetes mellitus, obesity, respiratory symptoms, and gastrointestinal symptoms than the general population. Many medications taken by patients with schizophrenia are associated with serious side effects that include metabolic disturbances and hepatic and/or renal impairment. Such medication side effects can lead to non-adherence that can negatively impact psychiatric symptoms (Muir-Cochrane et al., 2008). People with schizophrenia are also more at risk of engaging in risky behaviors and contracting infectious diseases such as hepatitis C and human immunodeficiency virus (Muir-Cochrane et al., 2008).

People with schizophrenia also experience a number of mental health and substance abuse co-morbidities. Obsessive compulsive disorder, for example, is increasingly recognized as a comorbidity in schizophrenia, and it is estimated that 20% of people with schizophrenia experience obsessive compulsive disorder (Yum, Cleary, Hwang, Nasrallah & Opler, 2016). Fifty percent of people with schizophrenia also suffer from comorbid substance abuse over their lifetime (Bridgman, Ouellet-Plamondon, Morozova & George, 2013). Due to the complex interactions between substance abuse and schizophrenia, people with a dual diagnosis experience more severe symptoms and poorer prognosis (Bridgman et al., 2013). People with schizophrenia also experience a high risk of suicide. One out of three will attempt suicide, and one out of ten will die as a result (CDC, 2013).

More than half of people with schizophrenia are not receiving appropriate healthcare (WHO, 2016). They experience greater lack access to mental health services and medical care in general compared to the general population (Muir-Cochrane et al., 2008; WHO, 2016). People with schizophrenia are also less likely to see a general practitioner, receive continuity of care, and receive health promotion information compared to the general population (Muir-Cochrane et al., 2008). Mental health providers often do not pay sufficient attention to the physical health of people with schizophrenia, and these patients may be unable to articulate their medical problems clearly (Muir-Cochrane et al., 2008). Additionally, adopting healthy behaviors is likely to be more difficult for people with schizophrenia compared to the general population (Muir-Cochrane et al., 2008).

Schizophrenia is associated with a number of social, occupational, and economic negative effects. People with schizophrenia, for example, experience high degrees of stigma that are associated with social isolation, limited life opportunities, decreased QoL, and delayed help seeking (Bouwmans, De Sonneville, Mulder & Hakkaart-van Roijen, 2015; Kelly, 2005). Research indicates that the severity of positive, negative, and cognitive symptoms in people with schizophrenia is associated with job loss and lower chances of competitive employment (Bouwmans et al., 2015).

The economic burden of schizophrenia is rapidly increasing. The cost of schizophrenia in the United States was estimated to be $62.7 billion in 2002 and $155.7 billion in 2013 (Cloutier et al., 2016; McEvoy, 2007). The direct costs include inpatient and outpatient treatments and criminal justice involvement, and the indirect costs include loss of productivity for patients due to unemployment and premature mortality and loss of productivity for family caregivers (Cloutier et al., 2016; McEvoy, 2007).

HRQoL

Due to the severity and persistence of the symptoms of the illness and associated comorbidities, people with schizophrenia often experience challenges to their HRQoL (Barnes, Murphy, Fowler & Rempfer, 2012; WHO, 2016). The terms health, QoL, and HRQoL are sometimes used interchangeably but have different meanings. Health is "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 2018). QoL is a subjective evaluation of both positive and negative aspects of life (CDC, 2016). According to Healthy People 2020, HRQoL is "a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning. It goes beyond direct measures of population health, life expectancy, and causes of death, and focuses on the impact health status has on quality of life" (p. 1). The term HRQoL thus narrows the focus of the term QoL to domains that are influenced by health status (Chan, Hsiung, Thompson, Chen & Hwu, 2007).

Fit to National/International Research Priorities

Understanding HRQoL in people with schizophrenia is consistent with national nursing research priorities. The 2016 strategic plan of the National Institute of Nursing Research identifies wellness and the promotion of HRQoL for individuals with chronic conditions as research priorities. Moreover, improving the HRQoL of all people is a goal set by the Centers for Disease Control and Prevention (CDC, 2016), Healthy People 2020 (Healthy People 2020, 2016), and the World Health Organization (WHO, 2018). Gaining more information about HRQoL in groups of people with chronic conditions could lead to improved healthcare treatments/strategies as well as have important health policy implications (CDC, 2016).

HRQoL in People with Schizophrenia

HRQoL is used increasingly as an outcome measure in schizophrenia research and practice. Mental health services are shifting from a focus on disease and treatment to a more holistic approach to care that emphasizes complementary approaches to address well-being and functioning (Bouwmans et al., 2015). Improving the HRQoL of people with schizophrenia in the community has also become an important public health goal (Nakamura, Watanabe & Matsushima, 2014). The goal of improving the HRQoL calls for the integration of physical, psychological, and social care (CDC, 2016).

A better understanding of HRQoL and its determinants in people with schizophrenia may help guide preventive and rehabilitative efforts (Shepherd, Depp, Harris, Halpain, Palinkas & Jeste, 2012). Yet research on HRQoL in people with chronic illness is still at an early stage and is hindered by lack of consistent conceptualizations and a poor understanding of HRQoL in specific populations (Bakas, McLennon, Carpenter, Buelow, Otte, Hanna & Welch, 2012). Moreover, measurement of HRQoL in people with serious mental illness represent a particular challenge for researchers and clinicians (Barnes et al., 2012; CDC, 2016). In order to guide future research and the development of new treatments that address HRQoL in people with schizophrenia (Nakamura et al., 2014), more foundational research is needed to understand HRQoL in this population. Exploring HRQoL in people with schizophrenia will contribute to the advancement of the interdisciplinary sciences of nursing, health promotion, and psychology.

Theoretical Perspective

This dissertation was guided by a conceptual framework on HRQoL developed by Ferrans, Zerwic, Wilbur and Larson (2005). Ferrans et al. (2005) revised a model that had been created by Wilson and Cleary (1995) in order to clarify its taxonomy, facilitate its use, and suggest applications to practice. Because the revised model is more complete, clear, and realistic (Bakas et al., 2012), it will serve as the conceptual model for this dissertation.

The HRQoL conceptual model (Ferrans et al., 2005) is depicted in Figure 1.1. The model is centered on five health outcomes as follows: biological function, symptoms, functional status, general health perceptions, and overall QoL. Biological function includes processes at the level of cells, organs, and systems. Symptoms are people's perceptions of abnormal physical, emotional, or cognitive states. Functional status is the ability to perform tasks related to physical, psychological, and social functions. General health perception is people's subjective global evaluation of their health status. Overall quality of life is people's perception of how happy or satisfied they are with their lives in general.

The model indicates that these health outcomes are influenced by characteristics of the individual and characteristics of the environment. The characteristics of the individual purported to influence health outcomes include demographic, developmental, psychological, and biological factors. The characteristics of the environment purported to influence health outcomes are categorized as social or physical. Social influences include the influence of family, friends, and healthcare providers. Physical influences include the quality of home, neighborhood, and workplace.

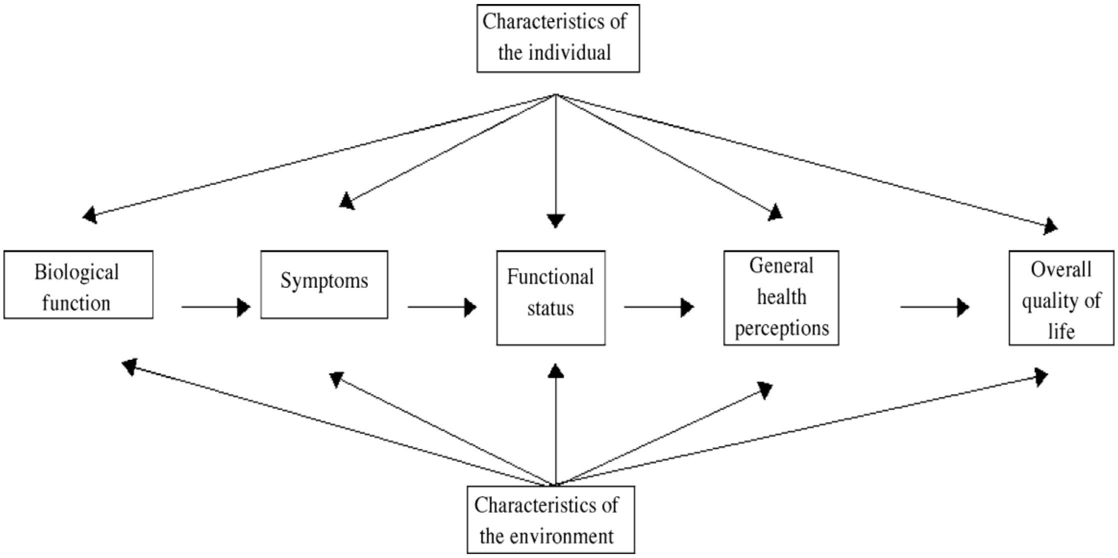

Figure 1.1. Conceptual Model of HRQoL (Ferrans et al., 2005)

Purpose and Specific Aims

The overarching goal of this dissertation is to conduct an in-depth exploration of HRQoL in people with schizophrenia. The specific aims are as follows:

Aim 1: Conduct an integrative review to identify and describe factors associated with physical QoL in people with schizophrenia.

Aim 2: Using qualitative descriptive methods, identify and describe common HRQoL concerns of people with schizophrenia based on their illness narratives.

Aim 3: Using a mixed method approach, explore whether computerized lexical analysis on life narratives of people with schizophrenia can reveal their HRQoL concerns.

The findings of each aim will be disseminated in Chapter 2 through 4. The findings related to Aim 1 will comprise Chapter 2 of the dissertation; the findings of Aim 2 will comprise Chapter 3; and the findings of Aim 3 will comprise Chapter 4. Chapter 5 will provide a summary and synthesis of Chapters 2 through 4. The resulting findings will advance the science of HRQoL in schizophrenia, provide a foundation for future studies, and point to avenues and targets for intervention aimed at promoting HRQoL in people with schizophrenia.

Methodological Perspectives

In order to address the study aims, several methodological perspectives were used. To address aim 1, an integrative review was conducted. To address aim 2, a qualitative descriptive approach was used. To address aim 3, a parallel convergent mixed methods design was used that involved quantitizing qualitative data and conducting a computerized lexical analysis. These methods are described below.

Integrative Review

Integrative review methods as outlined in the seminal work of Jackson (1980) and promoted for nurse researchers by Ganong (1987) were used to identify which factors were associated with physical QoL in people with schizophrenia in chapter 2. Integrative reviews are used to infer generalizations about substantive issues from a set of studies directly bearing on those issues (Ganong, 1987). Integrative review methods consist of systematic strategies including formulation of the review purpose, establishment of inclusion and exclusion criteria, design of a data collection tool to gather information from studies selected, and systematic analysis of data (Jackson, 1980, Ganong, 1987).

Qualitative Descriptive Analysis

The goal of qualitative descriptive analysis is to use low interpretive inductive analyses to provide a coherent and useful summary of events in everyday words. Qualitative descriptive analysis is the preferred method to provide a straightforward description of phenomena in a manner that is relevant to practitioners and policy makers. Qualitative content analysis is the analytic strategy used most frequently in qualitative descriptive approaches (Sandelowski, 2000). Because the goal of the current study was to provide a clear description of common HRQoL concerns as revealed by people with schizophrenia, qualitative descriptive analysis was deemed to be the most appropriate method.

Parallel Convergent Mixed Methods Design

Mixed methods research is defined as “research in which the investigator collects and analyzes data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or program of inquiry” (Teddlie & Tashakkori, 2006, p. 15). A mixed methods approach is typically associated with pragmatism. Pragmatism is a worldview that employs “what works,” using diverse approaches and valuing both objective and subjective knowledge (Creswell & Plano Clark, 2011).

In mixed methods studies, qualitative findings and quantitative findings are merged and provide value beyond the findings that would have resulted from the qualitative or quantitative strands alone (Creswell & Plano Clark, 2011). The mixed methods approach enables researchers to examine research problems with multiple approaches to enhance the validity and reliability of the findings (Creswell, 2012). Mixed methods research capitalizes on the strengths and offsets the weaknesses of both quantitative and qualitative research and enhances the rigor of the analytic process (Creswell & Plano Clark, 2011).

In a parallel convergent design, the qualitative strand and the quantitative strand are performed simultaneously. The purpose of this design is to use the strengths of each strand to compensate for the weaknesses of the other strand, to use the findings from one strand to confirm the findings from the other strand, and to investigate the extent to which the findings from both strands converge or diverge. For the purpose of this dissertation, I used a parallel convergent design to meet Aim 3.

Quantitizing Qualitative Data

Numerical transformations of narrative data can provide additional meaning to a set of findings (Sandelowski, 2001). Such transformations allow the use of descriptive and inferential statistics to identify patterns in the data and provide information about frequency and typicality of events. For example, the number of participants who contribute data to each category can suggest the robustness of that category among the sample as a whole. In the current study, determining the frequency with which the participants discussed each HRQoL concern or particular aspects of that concern, which have been identified by content analysis, provided information regarding the commonality of the concerns among the participants.

Computerized Lexical Analysis

Computerized lexical analysis is a quantitative approach in which words in text data are counted and sorted into pre-defined word categories (Junghaenel et al., 2008). Lexical analysis software programs are available to quantify text data efficiently (Firmin, Bonfils, Luther, Minor & Salyers, 2016). These programs provide detailed analyses about the words used in texts, the categories into which they fall, and the topics most represented in the data (Firmin et al., 2016). Lexical analysis is becoming increasingly nuanced and enables researchers to analyze quickly large amounts of data text (Firmin et al., 2016). For the purpose of this dissertation, I used the Linguistic Inquiry and Word Count (LIWC) program (LIWC2015; Pennebaker, Booth, & Francis, 2015) to address

Aim 3. LIWC is used widely in social sciences to calculate the percentage of text data that falls within domains relevant to psychological processes, emotions, and social relationships (Buck, Minor, & Lysaker, 2015; Minor et al., 2015). LIWC provides a fast and reliable method for analyzing narratives by grouping words into thematic categories (Minor et al., 2015).

Parent Study

Data for Aims 2 and 3 were drawn from a larger, on-going, parent study titled Assessing Disorganization, Cognition, and Insight in Serious Mental Illness. The study was funded by the School of Science at Indiana University- Purdue University Indianapolis (Minor et al., 2015).

Purpose

The parent study explores language, cognitive functioning, insight, and symptoms in individuals with serious mental illness. The purpose is to measure associations between disorganization, cognition, and insight in two groups: 1) persons diagnosed with a serious mental illness and 2) a healthy control group. The current study used only data obtained from the serious mental illness group. The inclusion criteria for this group were as follows: (1) ages 18 and above; (2) DSM-IV-TR or DSM-V diagnosis of schizophrenia, schizoaffective disorder, schizophreniform disorder, or psychotic disorder not otherwise specified as confirmed by medical record review; and (3) speak English fluently. Exclusion criteria were as follows: (1) history and/or current diagnosis of mood disorder with psychotic features; (2) documented evidence of intellectual disability (intelligence quotient < 70) based on medical record review; (3) current DSM-IV diagnosis of alcohol or drug dependence; and (4) history of neurological illness or Traumatic Brain Injury that resulted in loss of consciousness > five minutes.

Recruitment

All parent study procedures were approved by the Indiana University and Veterans Affairs (VA) Institutional Review Boards. Participants in the serious mental illness Group were recruited at a community mental health center, a psychiatric hospital, or the Veterans Administration (VA) medical center. Study flyers that contained information about the study and a telephone number to contact the study team were placed at each site. Participants in the healthy control group were recruited in the community through study flyers.

Individuals interested in participating were invited to contact the research team. If the research team determined that the participants met study criteria, a face-to-face meeting was scheduled. After verifying that the volunteers met the inclusion criteria, the researcher explained the purpose of the study, discussed the risks and benefits, and obtained written informed consent.

Data Collection

A trained research assistant collected data during face-to-face meetings held at a community mental health center. The following additional data was obtained from the medical record: demographic information; diagnosis; symptoms of psychiatric illness; social history; tobacco, alcohol, and illicit substance usage; living situation; employment; incarceration information; medical history; and medications. In addition to a number of survey instruments, the participants completed the Indiana Psychiatric Illness Interview survey (IPII) (Lysaker, Clements, Plascak-Hallberg, Knipscheer & Wright, 2002), a semi-structured narrative interview that was developed to assess illness narratives. The questions on the IPII are open-ended to allow participants to discuss topics that are important to them. The tone of the interview is intended to be conversational. The interviewer’s task is to elicit enough information to understand the story the participants are telling about their mental illness. All IPII's were conducted by trained research assistants and typically lasted 30 to 60 min. The interview includes the follow questions:

1. Tell me in as much details as possible the story of your life.
2. Can you tell me about stressors in your life over the past two years?
3. What has changed or stayed the same since you were diagnosed with mental illness?
4. What are your hopes for the future?

The interviews were conducted with 17 men and 3 women ranging in age from 24 years to 60 years. All had been diagnosed with schizophrenia or schizoaffective disorder. The IPII (Lysaker et al., 2002) narratives, which provided all the data for the current study, were transcribed by a research assistant at the Assertive Community Treatment (ACT), a research and training center focused on evidence-based mental health practices that support recovery in adults with serious mental illness. The transcripts were de-identified and checked for accuracy by the primary investigator of this dissertation. The primary investigator ascertained that the IPII (Lysaker et al., 2002) narratives contained rich information about the participants’ perceptions of their HRQoL and could provide ample data to meet the study aims.

Overview of Chapters 2 to 5

The overview of this dissertation is outlined here. Chapter 2 is an integrative review of the literature that examines factors associated with physical QoL in people with schizophrenia. Chapter 3 builds on Chapter 2 and presents the results of a qualitative descriptive analysis that identifies common HRQoL concerns of people with schizophrenia based on their illness narratives. Chapter 4 is a mixed methods study that focuses on the identification of the HRQoL concerns described in Chapter 3 and explores whether computerized lexical analysis on life narratives of people with schizophrenia can reveal their HRQoL concerns. Chapter 5 presents a synthesis of findings from Chapters 2 through 4, outlines the strengths and limitations of the dissertation, and discusses implications of the findings in regard to future research and practice.

CHAPTER 2

Chapter 2 describes an integrative review of the literature conducted to identify factors associated with physical QoL in people with schizophrenia.

Introduction

Physical quality of life (QoL) in people with schizophrenia can be diminished by high rates of co-occurring physical illness and somatic symptoms. QoL is a person’s subjective evaluation of both positive and negative aspects of life (CDC, 2016), whereas physical QoL refers more specifically to persons’ evaluation of their physical health and its effects on their well-being. Physical QoL includes persons’ evaluation of their general physical health, their level of physical functioning, the bodily pain they experience, and their work limitations due to their physical health (SF-36; Ware et al., 1993; WHOQOL-BREF; WHOQOL Group, 1998). Factors that are most associated with physical QoL in people with schizophrenia have not been well identified.

Research has shown that nearly three-fourths of people with schizophrenia have one chronic physical health condition, and one-half have two or more (Jones et al., 2004). Compared to the general population, people with schizophrenia have 2 times the rate of metabolic syndrome, 2.4 times the rate of diabetes (Correll, Ng-Mak, Stafkey-Mailey, Farrelly & Loebel, 2017), and 3 times the rate of mortality from cardiovascular disease (Muir-Cochrane, Cleary, Walter & Matheson, 2008). Each incremental cardiometabolic comorbidity is associated with an 8.3% increase in total hospital costs (Correll et al., 2017). Moreover, people with schizophrenia also have high rates of respiratory symptoms, gastrointestinal symptoms, hypertension, and infectious and sexually transmitted diseases (Muir-Cochrane et al., 2008; Nishanth, Chadda, Sood, Biswas &

Lakshmy, 2017). The onset of serious medical conditions occurs on average 10 years earlier in people with schizophrenia than the general public (Bahorik, Satre, Kline-Simon, Weisner & Campbell, 2017). Because of these physical illnesses, it is not surprising that the life expectancy of people with schizophrenia is two decades shorter than the general population (De Hert et al., 2011; Foldemo et al., 2014; Moore, Shiers, Daly, Mitchell & Gaughran, 2015). As research has demonstrated that the number of co-occurring medical conditions in people with schizophrenia is associated with lower overall QoL (Adewuya & Makanjuola, 2009; Dickerson et al., 2011; Gomes et al., 2016), it is likely that physical co-morbidities lower their physical QoL as well.

In addition to the influence of physical health conditions on the physical QoL of people with schizophrenia, their physical QoL is also likely affected directly or indirectly by health-risk behaviors, medication side effects, and poor medical care. For example, people with schizophrenia often have a poor diet, characterized by a high consumption of saturated fat and a low intake of fiber and fruit, that, coupled with a sedentary lifestyle, contributes to the development of metabolic abnormalities (Dipasquale et al., 2013; Muir-Cochrane et al., 2008). They also have high rates of risk behaviors regarding sex and substance use (Muir-Cochrane et al., 2008; Wang, Polimanti, Kranzler, Zhao & Gelernter, 2017), and these behaviors can result in infectious diseases such as hepatitis C and HIV (Muir-Cochrane et al., 2008). In addition, social factors, such as poverty and homelessness, which are associated with health risk behaviors and poor health status, likely contribute to medical comorbidities in people with schizophrenia (Janssen, McGinty, Azrin, Juliano-Bult & Daumit, 2015). Metabolic abnormalities, infectious disease, and other medication co-morbidities in turn are likely to affect physical QoL.

Moreover, many medications taken by patients with schizophrenia are associated with serious side effects that include metabolic disturbances and hepatic and/or renal impairment (Muir-Cochrane et al., 2008). Despite these high rates of co-occurring medical problems, people with schizophrenia are less likely to receive preventive health services and high quality medical care, which can lead to poor health status and thus lowered physical QoL (Janssen et al., 2015). People with schizophrenia are less likely to see a general practitioner, partner with health care providers on setting common goals, receive continuous care, and receive health promotion information (Muir-Cochrane et al., 2008).

A better understanding of physical QoL and the factors associated with it in people with schizophrenia can inform treatment by suggesting potential avenues and targets for intervention. Mental health services are shifting from a singular focus on disease and treatment of symptoms to a more holistic approach that incorporates alternative and complementary strategies to improve the QoL of people with schizophrenia (Bouwmans, De Sonneville, Mulder & Hakkaart-van Roijen, 2015; Nakamura, Watanabe & Matsushima, 2014). Because medical comorbidities in schizophrenia are now considered a major public health issue (Bahorik et al., 2017), integrated care models have been developed. Integrated care is the systematic coordination of primary care and behavioral and substance abuse services for people with schizophrenia and multiple healthcare needs (Substance Abuse and Mental Health Services Administration [SAMHSA], 2018). Evidence indicates that integrated care can improve health outcomes in people with schizophrenia (Naslund et al., 2017; SAMHSA, 2018).

In order to develop strategies that not only improve the physical health of people with schizophrenia but address their subjective perceptions of their physical well-being, more information is needed about factors that are associated with their physical QoL. While several reviews have investigated personal, social, illness, and treatment factors associated with QoL generally in people with schizophrenia (Alshowkan, Curtis & White, 2012; Pinikahana, Happell, Hope & Keks, 2002), no review has focused specifically on factors associated with physical QoL.

The aim of this review was to identify and describe factors associated with physical QoL in people with schizophrenia. According to Conn and Sells (2014), integrative reviews allow investigators to report the strength of associations among variables of interest and determine the ratio of studies that report significant associations to those that do not, thereby allowing conclusions about whether there is clear evidence supporting a linkage among variables. Because we sought to identify factors that evidence indicates are associated with physical QoL in people with schizophrenia, rather than statistically aggregate effect sizes across primary studies, an integrative review was conducted. Identifying these factors can inform practice and point to issues that might be addressed in the holistic or integrated treatment approaches in this population.

Methods

This review followed procedures for conducting an integrative review that were outlined in the seminal work of Jackson (1980) and promoted for nurse researchers by Ganong (1987). These procedures are widely used in the health sciences (Billay & Myrick, 2008). According to Ganong (1987), the following tasks comprise an integrative review: (1) formulation of the review purpose, (2) establishment of inclusion and exclusion criteria, (3) design of a data collection tool to gather information from studies selected, and (4) systematic analysis of data (Jackson, 1980, Ganong, 1987). For this review, we considered a factor as any construct measured in a study that had an index of correlation with physical QoL. The factors included demographic, intrapersonal, social, or illness/treatment-related variables.

Tasks 1 and 2: Purpose and Inclusion Criteria

The purpose of the review is presented above. The team established inclusion and exclusion criteria. The search focused on articles published in English from January 2008 to January 2018. This time period was chosen because the physical health of people with schizophrenia has become a prominent concern primarily within the past decade (Muir-Cochrane et al., 2008; Buhagiar, Parsonage & Osborn, 2011; Bahorik et al., 2017).

The inclusion criteria were as follows: (a) quantitative research study, (b) sample included at least 50% of participants who had a diagnosis of schizophrenia, (c) measured physical QoL, (d) measured a variable representing a factor potentially associated with physical QoL, and (e) included a numerical index of correlation between physical QoL and the factor. The following types of articles were excluded: (a) literature reviews, (b) pilot studies, (c) study protocols, (d) editorials, (e) intervention/treatment studies, and (f) psychometric validations.

The database Medline (EBSCO) was searched using the key words "(schizop* or schizoaff*) and (quality of life)." Because studies use a variety of terms to reflect the construct of QoL, and physical QoL more specifically, we limited the search to those studies that used an instrument that had a distinct subscale that measured the construct of physical QoL. The primary investigator compiled a table that displayed (a) the names of the instruments; (b) subscales of each instrument, highlighting those that were related to any domains of physical health; (c) descriptions of the subscales; and (d) when available, examples of items. Instruments for which it was impossible to separate physical QoL scores from composite scores or that had no English translation were eliminated. The instruments that were determined to have unique subscales measuring physical QoL and the titles of which were entered as search terms included the World Health Organization Quality of Life Scale-Brief version (WHOQOL-BREF; WHOQOL Group, 1998), the Quality of Life Enjoyment and Life Satisfaction Questionnaire (Q-LES-Q; Endicott et al., 1993), the Schizophrenia Quality of Life Questionnaire (S-QoL; Auquier et al., 2003), the Short Form Health Survey (SF-36; Ware et al., 1993), the Wisconsin Quality of Life Index for Mental Health (QLI-MH; Becker et al., 1993), the Veterans RAND 12-Item Health Survey (VR-12; Kazis et al., 1999), the Quality of Life Self-Assessment Inventory (QLS-100; Skantze et al., 1994), the EuroQOL Five Dimensions Questionnaire (EQ5D; EuroQol Group, 1990), and the Modular System for Quality of Life (MSQOL; Pukrop et al., 2000).

The principal investigator independently reviewed each article for adherence to inclusion and exclusion criteria. A Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram (Moher, Liberati, Tetzlaff, Altman & the PRISMA Group, 2009) was used to record this process and reasons for article exclusion (Figure 2.1). Fifty-seven articles met the inclusion criteria.

Task 3: Data Collection Tool

The primary investigator set the following criteria to reflect clear evidence of associations between any particular factor and physical QoL: (1) at least 5 studies examined the association between the factor and physical QoL, and (2) at least 80% of those studies found significant associations in a similar direction between the factor and physical QoL. This strategy was chosen to ensure a factor had adequate coverage in the literature and to highlight those factors which showed clear evidence of an association with physical QoL. We then grouped all the studies that measured the same factor (e.g., positive symptoms) or closely related factors (e.g., body mass index, total body fat) (see Table 2.1).

Information from articles measuring factors that met our clear evidence criteria was extracted and organized into an evidence table (Table 2.2). The information included the citation, the study design, the sample composition, the setting, the definition and measure of QoL, the definition and measure of all variables for which indices of correlation with physical QoL were presented, and correlations between these variables and physical QoL. The selection of the articles and the information included in the tables were verified by other team members. On the tables, the articles that revealed significant findings are not shaded and those with non-significant findings are shaded in gray.

Task 4: Data Analysis

To systematically analyze the data, we recorded the evidence that supports associations between the factors and physical QoL. We documented the number of studies that examined the associations, the number of studies that revealed significant associations, the instruments used to measure the factors, and the range of the strength of associations. We then noted the limitations of the studies. Consistent with Cohen's (1992) criteria for correlation coefficients, effect sizes > .1 were considered small, > .3 were considered medium, and >.5 were considered large.

Findings

The review revealed that 57 articles explored associations between physical QoL and another factor, and all 57 articles showed significant associations between physical QoL and one or more factors. As seen in Table 2.1, factors were wide-ranging, and the number of studies examining each factor varied from one to twelve. Based on our pre-specified criteria for clear evidence, four factors were determined to be associated with physical QoL: symptoms of schizophrenia (general psychopathology and total symptoms), depression, body mass index/obesity, and physical activity. Twenty-eight of the 57 studies examined at least one of these factors and reported a significant association with physical QoL.

In 17 of these 28 studies the World Health Organization Quality of Life Assessment— Brief Form scale (WHOQOL-BREF; WHOQOL Group, 1998) was used to measure physical QoL. The WHOOQOL is a 26-item instrument that measures the following QoL domains: physical health, psychological health, social relationships, and environment. In the other 11 articles reviewed, only four other scales were used to measure physical QoL: The Short Form Health Survey (SF-36; Ware et al., 1992) was used in 7 studies, the Schizophrenia Quality of Life Questionnaire Short-Version (S-QoL 18; Boyer et al., 2010) was used in 2 studies, the Schizophrenia Quality of Life Questionnaire Chinese Version (S-QoL-C; Chou et al., 2011) was used in 1 study, and the Quality of Life Enjoyment and Life Satisfaction Questionnaire (Q-LES-Q; Endicott et al., 1993) was used in 1 study. The evidence that supports associations between the four factors and physical QoL is described below.

Symptoms of Schizophrenia and Physical QoL

Significant associations between symptoms of schizophrenia and physical QoL were found in 14 of the 17 studies that explored associations among these variables. These studies typically measured positive and negative symptoms of schizophrenia as well as general psychopathology and total symptoms. The majority of the articles used the Positive and Negative Syndrome Scale for Schizophrenia (PANSS; Kay et al., 1987) to measure the presence and severity symptoms in patients with schizophrenia. The PANSS is an instrument comprised of 30 items measuring the following subscales: positive symptoms, negative symptoms, and general psychopathology. Two other scales were used to measure severity of schizophrenia symptoms: The Brief Psychiatric Scale (BPRS; Hedlund et al., 1980) and the Clinical Global Impression Scale (CGI-S; Guy, 1976). While a number of studies found significant associations between positive (6 out of 9 studies) and negative symptoms (7 out of 11 studies) and physical QoL, these studies did not meet our 80% criteria for clear evidence. There was clear evidence, however, for associations between general psychopathology and total symptoms.

General psychopathology. General psychopathology was examined in six studies, and significant inverse associations with physical QoL were found in five. These studies included a general measure of psychopathology, including anxiety, poor attention and poor impulse control. All the studies were cross-sectional, and the samples ranged from 55 (Chugh, Rehan, Unni & Sah, 2013) to 100 (Akinsulore et al., 2014). The samples included outpatients (Akinsulore et al., 2014; Kokaçya et al., 2016; Sugawara et al., 2013; Woon, Chia, Chan & Sim, 2010), combined outpatients or inpatients (Ulaş, Polat, Akdede & Alptekin, 2010), or persons who recently had their first psychotic episode of schizophrenia spectrum disorder (Chugh et al., 2013). Several of the studies were conducted internationally, including in Singapore (Woon et al., 2010) and Turkey (Kokaçya et al., 2016). The correlations between total symptoms/general symptoms and physical QoL ranged from a small effect size, r = -.28, p<0.001 (Woon et al., 2010) to a large effect size, r = -.53, p<0.01 (Akinsulore et al., 2014). The one study that failed to find a significant association (Rodriguez et al., 2015) had a particularly low sample size (N = 36). The evidence thus provides strong support for the negative association between general psychopathology and physical QoL.

Total symptoms. Total symptoms were examined in eight studies, and significant inverse associations with physical QoL were found in seven. These studies included a measure of the total number of symptoms based on combined scores from symptom subscales, such as the positive symptoms, negative symptoms, and general psychopathology subscales of the PANSS (Kay et al. 1987). All the studies were cross-sectional, and the samples ranged from 72 (Ulas, Akdede, Ozbay & Alptekin, 2008) to 253 (Caqueo-Urízar et al., 2016). The samples included outpatients (Akinsulore et al., 2014; Brissos, Balanzá-Martinez, Dias, Carita & Figueira, 2011; Caqueo-Urízar et al., 2016; Munikanan et al., 2017; Sugawara et al., 2013), combined outpatients or inpatients (Ulas et al., 2008; Ulas et al., 2010), or persons who recently had their first psychotic episode of schizophrenia spectrum disorder (Chugh et al., 2013). Several of the studies were conducted internationally, including in Kuala Lumpur (Munikanan et al., 2017) and Portugal (Brissos et al., 2011). The correlations between total symptoms and physical QoL ranged from a small effect size, r = -.28, p<0.01 (Ulas et al., 2010) to a large effect size, r = -.53, p<0.01 (Akinsulore et al., 2014). The standardized coefficient (β) between total symptoms and physical QoL ranged from β = -.15, p ≤ 0.05 (Chou, Ma & Yang, 2014) to β = -.31, p=0.005 (Munikanan et al., 2017). The one study that failed to find a significant association (Brissos, Dias, Carita & Martinez-Arán, 2008) had a low sample size (N = 23). Overall, the evidence thus provides strong support for the negative association between total symptoms and physical QoL.

Depression

Depression was examined in 12 studies, and significant inverse associations were found with physical QoL in 10. All the studies were cross-sectional, and the samples ranged from 23 (Brissos et al., 2008) to 271 (Alessandrini et al., 2016). The samples included outpatients (Akinsulore et al., 2014; Alessandrini et al., 2016; Brissos et al., 2008; Kokaçya et al., 2016; Makara-Studzińska, Wołyniak & Kryś, 2012; Rayan, 2017), combined outpatients or inpatients (Chou et al., 2014; Ulas et al., 2008; Ulas et al., 2010), or persons who recently had their first psychotic episode of schizophrenia spectrum disorder (Ohmuro et al., 2017; Renwick et al., 2012). Several of the studies were conducted internationally, including in Nigeria (Akinsulore et al., 2014), Turkey (Kokaçya et al., 2016), and India (Chugh et al., 2013). Depression was measured with the CDSS (Addington and Schissel, 1990) in 4 studies, the BDI-II (Beck et al., 1996) in 2 studies, the Zung Self-Rating Depression Scale (Zung, 1965) in 1 study, the HDRS (Hamilton, 1960) in 1 study, the HADS (Zigmonda and Snaith, 1983) in 1 study, and the CES-D (Radloff, 1977) in 1 study. The correlation coefficients (r) between depression and physical QoL ranged from a medium effect size, r = -.31, p<0.0002 (Alessandrini et al., 2016) to a large effect size, r = -.81, p<0.001 (Ohmuro et al., 2017). The standardized coefficient (β) between depression and physical QoL ranged from β = -.29, p=0.001

(Chou et al., 2014) to $\beta = -4.66$, $p=0.003$ (Renwick et al., 2012). The two studies that failed to find significant associations (Brissos et al., 2011; Vancampfort et al., 2015) differed from the other studies as the instrument used to measure depression, the PANNS (Kay et al., 1987) and the Psychosis Evaluation Tool for Common Use by Caregivers (De Hert et al., 1998) were not developed as depression measures. Overall, therefore, the evidence provides strong support for the negative association between depression and physical QoL.

Body Mass Index or Obesity

Body mass index or obesity was examined in eight studies, and significant inverse associations were found in all of these studies. All the studies were cross-sectional, and the samples ranged from 31 (Kerling, Tegtbur, Ziegenbein, Grams, Heinze & Sieberer, 2013) to 1108 (Guo, Zhang, Zhai, Wu, Liu & Zhao, 2013). The samples included outpatients (Bressington et al., 2016; Gomes et al., 2016; Kerling et al., 2013; Kolotkin et al., 2008; Sugawara et al., 2013), inpatients (Vancampfort et al., 2015), or persons who recently had their first psychotic episode of schizophrenia spectrum disorder (Guo et al., 2013). Several of the studies were conducted internationally, including in China (Bressington et al., 2016), Brazil (Gomes et al., 2016), and Belgium (Vancampfort et al., 2011).

All studies calculated the participants' BMI. Several studies (Bressington et al., 2016; Gomes et al., 2016; Kerling et al., 2013; Vancampfort et al., 2011; Vancampfort et al., 2015) used the BMI score as an ordinal measure and others used BMI to categorize participants into varying weight categories: obese/non-obese (Kolotkin et al., 2008), normal weight/overweight/obese (Sugawara et al., 2013), and underweight/normal weight/overweight/obese (Guo et al., 2013).

Most studies measured physical QoL using either the SF-36 (Ware et al., 1992) or the SF12v2 (Ware et al., 1996). The correlation coefficients (r) between body mass index/obesity and physical QoL ranged from a small effect size, $r = -.27$, $p=0.013$ (Bressington et al., 2016) to a large effect size, $r = -.53$, $p<0.01$ (Kerling et al., 2013). The standardized coefficients (β) between body mass index/obesity and physical QoL ranged from $\beta = -.16$, $p<0.05$ (Sugawara et al., 2013) to $\beta = -.53$, $p <0.001$ (Vancampfort et al., 2011). This evidence thus provides strong support for the negative association between body mass index/obesity and physical QoL.

Physical Activity

Physical activity was examined in 5 studies. While significant positive associations were found in 4 studies, one study found an inverse association. All the studies were cross-sectional, and the samples ranged from 32 (Gomes et al., 2016) to 184 (Deenik et al., 2017). The samples included outpatients (Gomes et al., 2016), inpatients (Deenik et al., 2017; Vancampfort et al., 2015), or combined outpatients or inpatients (Heggelund, Hoff, Helgerud, Nilsberg & Morken, 2011). Several of the studies were conducted internationally, including in the Netherlands (Deenik et al., 2017), Norway (Heggelund et al., 2011), and Belgium (Vancampfort et al., 2015).

Physical activity was operationalized in a variety of ways. Two studies measured the frequency of physical activity using the “average total activity counts per hour” (Deenik et al., 2017, p. 3) or by measuring the minutes of physical activity per day and categorizing the activity as sedentary, light, moderate, vigorous, or most vigorous

(Gomes et al., 2016). Two studies measured the maximal oxygen uptake with the submaximal Astrand–Rhyming cycle ergometer test (Vancampfort et al., 2015) or the Metamax II portable metabolic test system (Heggelund et al., 2011). One study measured leisure time physical activity with the Baecke Physical Activity Questionnaire (Vancampfort et al., 2011), and another measured functional exercise capacity with the 6MWT test Vancampfort et al., 2011).

In the four studies that found positive associations, the correlation coefficients (r) between physical activity and physical QoL ranged from a medium effect size, $r = .47$, $p=0.013$ to a large effect size, $r = .58$, $p<0.001$ (Heggelund et al., 2011), and the standardized coefficients (β) ranged from $\beta = .43$, $p<0.001$ (Vancampfort et al., 2015) to $\beta = 1.18$, $p<0.05$ (Deenik et al., 2017). The one study that found that physical activity and physical QoL were inversely correlated $r = -.43$, $p=0.013$ (Gomes et al., 2016)had a low sample size ($N=32$) and focused on light physical activity. Overall, the evidence thus provides support for the positive association between physical activity and physical QoL.

Limitations of Included Studies

The findings should be understood in the context of the limitations of studies reviewed. One limitation to this body of work was the lack of conceptual clarity for the phenomena of physical QoL as it was not defined in most studies. A second limitation was that the cross-sectional nature of the studies prohibits the determination of causality among the factors and physical QoL. Moreover, while there was a fair amount of consistency across articles in the use of the WHOQOL (WHOQOL Group, 1998) to measure physical QoL and the PANSS (Kay et al., 1987) to measure symptoms of schizophrenia, the factors of depression, BMI, and obesity were measured using a wide variety of tools. Consistency across measures would facilitate comparing results across studies.

Discussion

This review included 57 studies that examined associations between physical QoL in people with schizophrenia and a number of different factors including symptoms of schizophrenia, mental health comorbidities, and psychosocial factors. Many studies found significant associations between particular factors and physical QoL, but most of the factors were examined in a small number of studies and thus conclusions could not be drawn about their associations with physical QoL. Based on our clear evidence criteria (e.g., at least 5 studies tested the association between a factor and physical QoL and at least 80% of the studies revealed a significant association in the same direction between the factor and physical QoL), we concluded that there is enough evidence to suggest that physical QoL was associated with the following factors: (a) symptoms of schizophrenia, including the level of general psychopathology and the total number of symptoms, (b) depression, (c) obesity or body mass index, and (d) physical activity.

The associations between symptoms of schizophrenia and physical QoL could be expected, giving that the illness is known to have a pervasive impact on all aspects of persons’ well-being and functioning (Chugh et al., 2013; Kokaçya et al., 2016). The pathways between symptoms of schizophrenia and physical QoL, however, have not been well-explicated. One likely pathway is that the severity of schizophrenia symptoms causes deleterious effects on persons’ physical health, which in turn affects their physical QoL. Yet, although people with schizophrenia are more likely to experience physical comorbidities than the general population (Correll et al., 2017; Muir-Cochrane et al., 2008), few studies have tested the proposed pathways linking schizophrenia symptoms, physical health problems, and poor physical QoL. Another pathway might be that deteriorating physical health and decreases in physical QoL lead to symptom exacerbation. Although several studies found significant inverse associations between positive (6 out of 9 studies) and negative symptoms (7 out of 11) and physical QoL, these studies did not meet our evidence criteria because less than 80% of the studies revealed significant associations. However, given that the majority of these articles did find significant correlations, we surmise that future research will provide more evidence for these associations, and positive and negative symptoms will be factors that play a role in predicting physical QoL. Overall, the pathways between schizophrenia symptoms and physical QoL are likely to be complicated, and longitudinal studies are needed to better explicate the directionality and complexity of these pathways.

Most studies in our review that examined associations between depression and physical QoL in people with schizophrenia found significant inverse relationships. Depression is estimated to be present in up to 80% of people with schizophrenia and is associated with a host of other factors including more severe positive symptoms and general psychopathology, lower general and occupational functioning (Grover, Sahoo, Nehra, Chakrabarti & Avasthi, 2017), suicide attempts (Kocaturk, Essizoglu, Aksaray, Akarsu & Musmul, 2015), and lower QoL in all domains (Alessandrini et al., 2016; Makara-Studzińska et al., 2011). As with symptoms of schizophrenia, the pathways connecting depression and physical QoL are likely to be complex. Because depression is associated with elevated physical comorbidities such as cancer, stroke, and heart disease in all persons (Aragonès, Piñol & Labad, 2007; Hee-Ju et al., 2015), it is likely that depression is associated with similar physical illnesses in people with schizophrenia, which in turn could affect their physical QoL. In addition, depression negatively affects people's self-evaluation of their functioning and autonomy and this in turn affect how they perceive their physical well-being (Alessandrini et al., 2016). Moreover, feelings of worthlessness and self-depreciation often associated with depression may negatively impact functioning and consequently physical QoL (Alessandrini et al., 2016).

All studies in our review that examined BMI and physical QoL in people with schizophrenia found significant inverse relationships. The pathway between these two factors likely involves a number of health-risk behaviors and physical comorbidities. For example, poor diet, a sedentary lifestyle, lack of physical activity, and side effects of neuroleptics are associated with higher BMI in people with schizophrenia (Kerling et al., 2013; Sugawara et al., 2013; Vancampfort et al., 2011). High BMI in turn is associated with a host of physical problems including type 2 diabetes, stroke, hyperlipidemia, coronary artery disease, hypertension, and cancer (Strassnig et al., 2017). The presence of these illnesses thus could explain the relationship between BMI and physical QoL. Moreover, obesity in this population is often associated with life-style limitations such as lower physical functioning, restricted activities of daily living, and limited exercise (Strassnig et al., 2017, Vancampfort et al., 2011), all of which could diminish persons' perceptions of their physical well-being.

Most studies in our review that examined physical activity and physical QoL in people with schizophrenia found significant positive relationships. Among the factors that met our clear evidence criteria, physical activity is the only one that was positively associated with physical QoL. The relationship between physical activity and physical

QoL could be expected, given that physical activity is known to decrease schizophrenia symptoms and depression (Rosenbaum, Tiedemann, Sherrington, Curtis & Ward, 2014) and to improve cognitive functioning (Firth et al., 2017), all of which have been linked to higher physical QoL. Another pathway might be that physical activity promotes better physical health and in turn leads to higher physical QoL. Despite growing evidence of the benefits of physical activity in people with schizophrenia, this population rarely engages in routine physical activity (Soundy et al., 2013). Research suggests that barriers to the physical activity in this population include lack of knowledge about cardiovascular disease and the benefits of physical activity as well as social isolation (Soundy, Stubbs, Probst, Hemmings & Vancampfort, 2014b; Vancamfort et al., 2013).

Our findings should be understood in the context of the limitations of the integrative review in addition to the limitations of the studies included in the review as described above. We included only studies that were written in English, and this might have limited some international studies. However, the sample did included studies from countries from most regions of the world. In addition, we searched only the Medline database, and despite extensiveness of this database, some studies that were not indexed there might have been excluded.

More studies need to be conducted on factors that research suggests, but has not substantiated, are associated with physical QoL. In particular, we recommend more research on mutable factors that might influence physical QoL, such as coping, self-esteem, and insight, as these factors would have important implications for psychosocial treatments. Future research should also include more cutting-edge studies on genetics and other biological factors that may influence physical QoL. For example, one study measured regional cerebral blood flow and found that perfusion of the right parahippocampal gyrus was positively associated with physical QoL (New Fei et al., 2017). It is possible that these biological factors have a role in the risk of developing physical health disorders and in turn impact physical QoL. Ultimately what is needed is a comprehensive biopsychosocial model that explicates the complex pathways leading to poor physical QoL in this population.

The findings of this review have implications for psychiatric mental health nurses and other mental health clinicians who work with people with schizophrenia. Because schizophrenia symptoms are consistently associated with physical QoL, clinicians can anticipate that best practices of symptom management may likely improve physical QoL. Whether clients are experiencing a remission of symptoms or not, a clinician can initiate discussions about how clients perceive their physical well-being and physical functioning. Similarly, clinicians should be aware that those clients with schizophrenia who also suffer from depression may be particularly likely to have a diminished view of their physical well-being. Although depression is often undertreated in this population (Addington, Azorin, Falloon, Gerlach, Hirsch & Siris, 2002), pharmacological and psychosocial treatments to address depression have been shown to be effective (Buchanan et al., 2010; Englisch, Inta, Eer & Zink, 2010; Tabak, Horan & Green, 2015). Similarly, treatments that have shown to effectively reduce obesity and increase physical activity in this population should be considered. For example, a systematic review revealed that walking groups helped individuals with schizophrenia reduce their weight and BMI (Soundy, Muhamed, Stubbs, Probst & Vancampfort, 2014a). Additionally, nutrition education, behavioral interventions, self-monitoring, and dietary changes have been shown to promote weight loss in overweight and obese adults with serious mental illness (Naslund et al., 2017). Due to relationships between schizophrenia symptoms, depression, and BMI/obesity and physical QoL, an integrated care approach for people with schizophrenia is warranted, and clinicians should advocate for delivery systems that approach psychiatric and physical well-being holistically.

Conclusion

People with schizophrenia often face debilitating psychiatric symptoms and physical comorbidities associated with high rates of morbidity and mortality and lowered QoL. With the aim of identifying factors that are associated with physical QoL in this population, the results of this review revealed that there is the most evidence to support the presence of associations between physical QoL and symptoms of schizophrenia, depression, BMI/obesity, and physical activity. More research is needed to explore the nature of these relationships and to explicate pathways that predict how a number of factors contribute to how people with schizophrenia perceive their physical health and well-being. The results of this review indicate that clinicians who work with people with schizophrenia should initiate discussions about how they perceive their physical QoL and, if indicated, consider interventions that not only address symptoms of schizophrenia but those that target depression and obesity, and physical activity as well.

Table 2.1

Summarized Evidence for Factors Associated with Physical QoL

Category	**Factor**	**Number of studies measuring factor**	**Number of significant negative associations found**	**Number of significant positive associations found**	**Significant associations: source**	**Nonsignificant associations: source**
Symptoms of schizophrenia	**Positive symptoms**	9	6	0	Akinsulore et al., 2014; Chugh et al., 2013; Kokaçya et al., 2016; Rodriguez et al., 2015; Ulas et al., 2010; Vancampfort et al., 2015;	Margariti et al., 2015; Brissos et al., 2011; Ohmuro et al., 2017;
	Negative symptoms	11	7	0	Akinsulore et al., 2014; Brissos et al., 2011; Kokaçya et al., 2016; Renwick et al., 2012; Ritsner et al., 2012a; Rodriguez et al., 2015; Woon et al., 2010;	Margariti et al., 2015; Ulas et al., 2010; Vancampfort et al., 2015; Ohmuro et al., 2017;
	General psychopathology	6	5	0	Akinsulore et al., 2014; Chugh et al., 2013; Kokaçya et al., 2016; Ulas et al., 2010; Woon et al., 2010;	Rodriguez et al., 2015;
	Total symptoms	7	6	0	Akinsulore et al., 2014; Munikanan et al., 2017; Caqueo-Urízar et al., 2016; Brissos et al., 2011; Sugawara et al., 2013; Ulas et al., 2008; Ulas et al., 2010;	Brissos et al., 2008;
	Excitatory	1	0	0		Vancampfort et al., 2015;

Category	Factor	Number of studies measuring factor	Number of significant negative associations found	Number of significant positive associations found	Significant associations: source	Nonsignificant associations: source
Mental health comorbidities	**Depression**	12	10	0	Alessandrini et al., 2016; Akinsulore et al., 2014; Brissos et al., 2008; Chou et al., 2014; Makara-Studzińska et al., 2012 ; Renwick et al., 2012; Ohmuro et al., 2017; Rayan., 2017; Ulas et al., 2008; Ulas et al., 2010;	Vancampfort et al., 2015; Brissos et al., 2011;
	Suicidality	3	3	0	Huang et al., 2014; Kao et al., 2012; Yan et al., 2013;	
	Anxiety or anxiety/ depression	3	3	0	Górna et al., 2008; Makara-Studzińska et al., 2012; Ohmuro et al., 2017;	
	Any mental health comorbidity	1	1	0	Huang et al., 2014;	
Substance use	**Smoking**	2	0	1	Munikanan et al., 2017;	Vancampfort et al., 2015;
	Substance abuse history	1	0	0		Huang et al., 2014;
Physical health comorbidities	**Body mass index, obesity**	8	8	0	Bressington et al., 2016; Gomes et al., 2016; Guo et al., 2013; Kerling et al., 2013; Kolotkin et al., 2008; Sugawara et al., 2013; Vancampfort et al., 2011;	

Category	**Factor**	**Number of studies measuring factor**	**Number of significant negative associations found**	**Number of significant positive associations found**	**Significant associations: source**	**Nonsignificant associations: source**
					Vancampfort et al., 2015;	
	Metabolic syndrome	2	2	0	Malhotra et al., 2016; Vancampfort et al., 2011;	
	Total body fat	1	1	0	Strassnig et al., 2012;	
	Pain	1	1	0	Almeida et al., 2013;	
Functioning	**General functioning**	3	0	3	Akinsulore et al., 2014; Kokaçya et al., 2016; Ritsner et al., 2012b;	
	Cognitive functioning	6	0	4	Rodriguez et al., 2015; Williams et al., 2008; Woon et al., 2010;	Ulas et al., 2008; Alessandrini et al., 2016;
	Social functioning	3	1	2	Fontanil-Gómez et al., 2017; Huang et al., 2014; Woon et al., 2010;	
	Executive function	1	0	0		Boyer et al., 2012;
Illness and Treatment Factors	**Severity of illness**	3	3	0	Huang et al., 2014; Kokaçya et al., 2016; Ritsner et al., 2012b;	
	Medication side effects	3	3	0	Bebbington et al., 2009; Staring et al., 2009; Yen et al., 2008;	
	Remission status (in remission)	3	0	3	Helldin et al., 2008; Kokaçya et al., 2016; Madhivanan et al., 2017;	
	Age of illness onset	2	1	0	Brissos et al., 2011;	Kokaçya et al., 2016;
	Duration of illness	2	2	0	Kokaçya et al., 2016; Vancampfort et al., 2015;	Huang et al., 2014; Yen et al., 2008; Munikanan et al., 2017;

Category	**Factor**	**Number of studies measuring factor**	**Number of significant negative associations found**	**Number of significant positive associations found**	**Significant associations: source**	**Nonsignificant associations: source**
	Previous hospital admission	1	0	1	Huang et al., 2014;	
	Duration of untreated psychosis	1	1	0	Górna et al., 2008;	
	Inpatient vs outpatient	1	0	1	Renwick et al., 2012;	
	Medication adherence	3	0	1	Sugawara et al., 2013;	Huang et al., 2014; Yen et al., 2008;
Satisfaction with service		2	0	2	Afe et al., 2016; Zendjidjian et al., 2014;	
Physical activity		5	1	4	Deenik et al., 2017; Gomes et al., 2016; Heggelund et al., 2011; Vancampfort et al., 2011; Vancampfort et al., 2015;	
Spirituality	**Spirituality**	2	0	2	Shah et al., 2011; Triveni et al., 2017;	
	Religion involvement	1	0	0		Caqueo-Urízar et al., 2016;
Psychosocial factors	**Mindfulness**	1	0	1	Rayan., 2017;	
	Positive coping strategies	1	0	1	Holubova et al., 2015;	
	Negative coping strategies	1	1	0	Holubova et al., 2015;	
	Self-esteem	1	1	0	Chou et al., 2014;	
	Self-stigma	1	1	0	Mosanya et al., 2014;	

Category	Factor	Number of studies measuring factor	Number of significant negative associations found	Number of significant positive associations found	Significant associations: source	Nonsignificant associations: source
	Psychological distress	1	1	0	Huang et al., 2014;	
	Emotional distress	1	1	0	Ritsner et al., 2012a;	
	Insight	5	2	2	Boyer et al., 2012; Karow et al., 2008; Yen et al., 2008; Margariti et al., 2015;	Brissos et al., 2011;
Living arrangement	**Living with family or caregiver**	2	0	2	Fontanil-Gómez et al., 2017; Huang et al., 2014;	
	Outpatients vs foster care	1	0	1	Mihanovic et al., 2015;	
	Homelessness	1	1	0	Van der Plas et al., 2012;	
	Living in own home	1	0	0		Huang et al., 2014;
Social environment	**Social support**	2	0	2	Munikanan et al., 2017; Yen et al., 2008;	
	Family burden	1	1	0	Huang et al., 2014;	
	Negative caregiver attitude	1	1	0	Huang et al., 2014;	
	Having a caregiver	1	0	0		Huang et al., 2014;
	Social support from friends	1	0	0		Munikanan et al., 2017;
Work load		1	0	0		Kerling et al., 2013;
Violence history		1	1	0	Huang et al., 2014;	

Category	Factor	Number of studies measuring factor	Number of significant negative associations found	Number of significant positive associations found	Significant associations: source	Nonsignificant associations: source
Legal problems		1	0	0		Huang et al., 2014;
Demographics	**Age**	9	4	1	Brissos et al., 2011; Folsom et al., 2009; Huang et al., 2014; Sugawara et al., 2013; Vancampfort et al., 2015;	Yen et al., 2008; Boyer et al., 2012; Kokaçya et al., 2016; Kerling et al., 2013;
	Education level	5	0	1	Górna et al., 2008;	Huang et al., 2014; Yen et al., 2008; Boyer et al., 2012; Kokaçya et al., 2016; Caqueo-Urízar et al., 2016;
	Employment status	3	0	1	Huang et al., 2014;	Boyer et al., 2012; Munikanan et al., 2017;
	Marital status (being married)	3	1	0	Huang et al., 2014;	Boyer et al., 2012; Munikanan et al., 2017;
	Gender (female)	4	1	1	Sugawara et al., 2013; Munikanan et al., 2017;	Yen et al., 2008; Caqueo-Urízar et al., 2016;
	Ethnicity	2	0	0		Caqueo-Urízar et al., 2016; Munikanan et al., 2017;
Biological	**Phenotype**	1	0	1	McGrath et al., 2013;	
	Regional cerebral blood flow	1	0	1	Faget-Agius et al., 2016;	
Unmet needs		1	1	0	Ritsner et al., 2015;	

Table 2.2

Factors Associated with Physical QoL

Source	**Methods**	**Sample**	**Physical QoL**	**Factors associated with physical QoL**	**Association between factors and physical QoL domains**
Symptoms of schizophrenia: General psychopathology					
Akinsulore et al., (2014)	<u>Design:</u> Cross-sectional <u>Setting:</u> Outpatients in Nigeria.	N=100 <u>Mean age:</u> 40 <u>51 males and 49 females</u>	<u>Physical QoL domain(s):</u> Physical health <u>Measure:</u> The World Health Organization Quality of Life Scale-Brief version (WHOQOL-BREF; WHOQOL Group, 1998).	**General psychopathology** <u>Definition:</u> None <u>Measure:</u> The Positive and Negative Syndrome Scale for Schizophrenia (PANSS; Kay et al., 1987).	General psychopathology was negatively associated with the physical health domain (r=-0.534, p<0.01).
Chugh et al., (2013)	<u>Design:</u> Cross-sectional <u>Setting:</u> First episode outpatients in a tertiary care hospital in New Delhi, India.	N=55 <u>Mean age:</u> 23 <u>36 males and 19 females</u>	<u>Physical QoL domain(s):</u> Physical <u>Measure:</u> The World Health Organization Quality of Life Assessment— Brief Form scale (WHOQOL-BREF; WHOQOL Group, 1998).	**General psychopathology** <u>Definition:</u> None <u>Measure:</u> The Positive and Negative Symptom Scale for Schizophrenia (PANSS; Kay et al. 1987).	General psychopathology was negatively associated with the physical domain (r=-0.347, p<0.05).
Kokaçya et al., (2016)	<u>Design:</u> Cross-sectional <u>Setting:</u> Outpatients from Gaziantep, Turkey.	N=80 <u>Mean age:</u> Patients with remission (37) and patients without remission (34). <u>47 males and 33 females</u>	<u>Physical QoL domain(s):</u> Physical <u>Measure:</u> The World Health Organization Quality of Life assessment— Brief Form scale Turkish Version (WHOQOL-BREF-TR; WHOQOL Group, 1998).	**General psychopathology** <u>Definition:</u> None <u>Measure:</u> The Positive and Negative Syndrome Scale for Schizophrenia (PANSS; Kay et al., 1987).	General psychopathology was negatively associated with the physical domain (r=-0.308, p=0.054).

Source	**Methods**	**Sample**	**Physical QoL**	**Factors associated with physical QoL**	**Association between factors and physical QoL domains**
Ulas et al., (2010)	Design: Cross-sectional Setting: Inpatients and outpatients from psychiatry clinics of the Medical School of Dokuz Eylül University, Turkey.	N=88 Mean age: 35 54 males and 34 females	Physical QoL domain(s): Physical Measure: The World Health Organization Quality of Life Schedule Brief version (WHOQOL-BREF; The WHOQOL Group, 1998).	**General psychopathology** Definition: None Measure: The Positive and Negative Syndrome Scale for Schizophrenia (PANSS; Kay et al., 1987)	General psychopathology was negatively associated with the physical domain (r=-0.39, p<0.001).
Woon et al., (2010)	Design: Cross-sectional Setting: Outpatients form the institute of Mental Health, Singapore.	N=83 Mean age: 30 53 males and 30 females	Physical QoL domain(s): Physiscal Measure: The World Health Organization Quality of Life Schedule Brief version (WHOQOL-BREF; The WHOQOL Group, 1998).	**General psychopathology** Definition: None Measure: The Positive and Negative Syndrome Scale for Schizophrenia (PANSS; Kay et al., 1987).	General psychopathology was negatively associated with the physical domain (r=-0.28, p<0.001)
Rodriguez et al., (2015)	Design: Cross-sectional Setting: First episode patients from the National Institute of Mental Health, Klecany, Czech Republic.	N=36 Mean age: 26 22 males and 14 females	Definition: None Measure: The World Health Organization Quality of Life Schedule Brief version (WHOQOL-BREF; The WHOQOL Group, 1998).	**General psychopathology** Definition: None Measure: The Positive and Negative Symptom Scale for Schizophrenia (PANSS; Kay et al. 1987).	Non-significant association between general psychopathology and the physical domain (β=- 0.079, p=0.628).

Source	Methods	Sample	Physical QoL	Factors associated with physical QoL	Association between factors and physical QoL domains
Symptoms of schizophrenia: Total symptoms					
Akinsulore et al., (2014)	Design: Cross-sectional Setting: Outpatients in Nigeria.	N=100 Mean age: 40 51 males and 49 females	Physical QoL domain(s): Physical health Measure: The World Health Organization Quality of Life Scale-Brief version (WHOQOL-BREF; WHOQOL Group, 1998).	**Total symptoms** Definition: None Measure: The Positive and Negative Syndrome Scale for Schizophrenia (PANSS; Kay et al., 1987).	Total symptoms were negatively associated with the physical health domain (r=-0.605, p <0.01).
Munikanan et al., (2017)	Design: Cross-sectional Setting: Outpatients from community psychiatric services in Hospital Kuala Lumpur.	N=160 Mean age: Not reported 101 males and 59 females	Physical QoL domain(s): Physical Measure: The World Health Organization Quality of Life Schedule Brief version (WHOQOL-BREF; The WHOQOL Group, 1998).	**Symptom severity** Definition: None Measure: The Brief Psychiatric Scale (BPRS; Hedlund et al., 1980).	Symptom severity were negatively associated with the physical domain (β=-0.310, p=0.005).
Caqueo-Urízar et al., (2016)	Design: Cross-sectional Setting: Outpatients from mental health services in Bolivia (N = 83), Chile (N = 85) and Peru (N = 85).	N=253 Mean age: 35 164 males and 83 females	Physical QoL domain(s): physical well-being Measure: The Schizophrenia Quality of Life Questionnaire (SQoL18; Boyer et al., 2010).	**Total symptoms** Definition: None Measure: The Positive and Negative Syndrome Scale for Schizophrenia (PANSS; Kay et al., 1987).	Total symptoms were negatively associated with the physical well-being domain (β=-0.15, p≤0.05).
Brissos et al., (2011)	Design: Cross-sectional Setting:	N=76 Mean age: 39 56 males and 20 females	Physical QoL domain(s): Physical Measure:	**Total symptoms** Definition: None Measure:	Total symptoms were negatively associated with the physical domain (r=-0.366, p< 0.01).

Source	Methods	Sample	Physical QoL	Factors associated with physical QoL	Association between factors and physical QoL domains
	Outpatients from 2 psychiatric departments in Lisbon, Portugal.		The World Health Organization Quality of Life Assessment— Brief Form scale (WHOQOL-BREF; WHOQOL Group, 1998).	The Positive and Negative Syndrome Scale for Schizophrenia (PANSS; Kay et al., 1987).	
Sugawara et al., (2013)	Design: Cross-sectional Setting: Outpatients in Japan.	N=225 Mean age: 42 106 males and 119 females	Physical QoL domain(s): Physical functioning and physical composite score. Measure: The Short Form Health Survey (SF-36; Ware et al., 1992).	**Symptom severity** Definition: None Measure: The Clinical Global Impression Scale (CGI-S; Guy, 1976).	Symptom severity was negatively associated with the following domains: physical functioning (β=-0.218, p<0.001), role physical functioning (β=-0.304, p<0.001), body pain (β=-0.304, p<0.001), vitality (β=-0.208, p<0.01), and physical composite score (β=-0.320, p<0.01).
Ulas et al., (2008)	Design: Cross-sectional Setting: Inpatients and outpatients from psychiatry clinics of the Medical School of Dokuz Eylül University, Turkey.	N=72 Mean age: 33 44 males and 28 females	Physical QoL domain(s): Physical Measure: The World Health Organization Quality of Life Schedule Brief version (WHOQOL-BREF; The WHOQOL Group, 1998).	**Total symptoms** Definition: None Measure: The Positive and Negative Syndrome Scale for Schizophrenia (PANSS; Kay et al., 1987).	Total symptoms were negatively associated with the physical domain (r=-0.5, p<0.001).
Ulas et al., (2010)	Design: Cross-sectional Setting:	N=88 Mean age: 35 54 males and 34 females	Physical QoL domain(s): Physical Measure:	**Total symptoms** Definition: None Measure:	Total symptoms were negatively associated with the physical domain (r=-0.28, p<0.01).

Source	Methods	Sample	Physical QoL	Factors associated with physical QoL	Association between factors and physical QoL domains
	Inpatients and outpatients from psychiatry clinics of the Medical School of Dokuz Eylül University, Turkey.		The World Health Organization Quality of Life Schedule Brief version (WHOQOL-BREF; The WHOQOL Group, 1998).	The Positive and Negative Syndrome Scale for Schizophrenia (PANSS; Kay et al., 1987)	
Brissos et al., (2008)	Design: Cross-sectional Setting: Outpatients from 2 psychiatric departments in Lisbon, Portugal.	N=23 Mean age: 39 Gender not reported	Physical QoL domain(s): Physical Measure: The World Health Organization Quality of Life Assessment— Brief Form scale (WHOQOL-BREF; WHOQOL Group, 1998).	**Total symptoms** Definition: None Measure: The Positive and Negative Syndrome Scale for Schizophrenia (PANSS; Kay et al., 1987).	Non-significant association between total symptoms and the physical domain (r=-0.322, p=>0.05).
Depression					
Akinsulore et al., (2014)	Design: Cross-sectional Setting: Outpatients in Nigeria	N=100 Mean age: 40 51 males and 49 females	Physical QoL domain(s): Physical health Measure: The World Health Organization Quality of Life Scale-Brief version (WHOQOL-BREF; WHOQOL Group, 1998).	**Level of depression** Definition: None Measure: The Zung Self-Rating Depression Scale (Zung, 1965).	Level of depression was negatively associated with the physical health domain (r=-0.616, p <0.01).
Alessandrini et al., (2016)	Design: Cross-sectional Setting: Community-dwelling	N=271 Mean age: 36 192 males and 79 females	Physical QoL domain(s): Physical well-being Measure: The Schizophrenia Quality of Life Short-Version (S-QoL 18; Boyer et al., 2010).	**Depressive symptoms** Definition: None Measure:	Severity of depressive symptoms was negatively associated with the physical well-being domain (r=-0.31, p<0.0002).

Source	Methods	Sample	Physical QoL	Factors associated with physical QoL	Association between factors and physical QoL domains
	outpatients in France.			The Calgary Depression Scale for Schizophrenia (CDSS; Addington and Schissel, 1990).	
Brissos et al., (2008)	Design: Cross-sectional Setting: Outpatients from 2 psychiatric departments in Lisbon, Portugal.	N=23 Mean age: 39 Gender not reported	Physical QoL domain(s): Physical Measure: The World Health Organization Quality of Life Assessment— Brief Form scale (WHOQOL-BREF; WHOQOL Group, 1998).	**Severity of depression** Definition: None Measure: The Hamilton Depression Rating Scale (HDRS; Hamilton, 1960).	Severity of depression was negatively associated with the physical domain ($r=-0.601$, $p<0.01$).
Chou et al., (2014)	Design: Cross-sectional Setting: Inpatients and outpatients from a hospital and a psychiatric daycare center in Taiwan.	N=120 Mean age: 41 80 males and 40 females	Physical QoL domain(s): Physical Measure: The Schizophrenia-specific S-QoL-C (Chou et al., 2011).	**Depressive levels** Definition: Self-reported depressive symptoms from patients' subjective perspectives. Measure: The Beck Depression Inventory-II (BDI-II; Beck et al., 1996).	Depressive levels were negatively associated with the physical domain ($\beta=-0.29$, $p=0.001$).
Makara-Studzińska et al., (2011)	Design: Cross-sectional Setting: Outpatients from psychiatric centers in Lublin, Poland.	N=115 Mean age: not reported Gender not reported	Physical QoL domain(s): Physical Measure: The World Health Organization Quality of Life assessment— Brief Form (WHOQOL-BREF; WHOQOL Group, 1998).	**Level of depression** Definition: Categorized as standard, mild, moderate, or severe. Measure: The Anxiety and depression scale, hospital anxiety and depression scale (HADS; Zigmonda and Snaith, 1983).	Level of depression was negatively associated with the physical domain ($p<0.001$).

Source	Methods	Sample	Physical QoL	Factors associated with physical QoL	Association between factors and physical QoL domains
Renwick et al., (2012)	Design: Cross-sectional Setting: First-episode patients form Dublin East Treatment and Early Care Team, Ireland.	N=146 Mean age: 32 89 males and 59 females	Physical QoL domain(s): Physical Measure: The World Health Organization Quality of Life Schedule Brief version (WHOQOL-BREF; The WHOQOL Group, 1998).	**Depressive symptoms** Definition: None Measure: The Calgary Depression Scale for Schizophrenia (CDSS; Addington et al., 1990).	Hopelessness (β=-4.23, p=0.004) and early morning wakening (β=-4.66, p=0.003) were negatively associated with the physical domain.
Ohmuro et al., (2017)	Design: Cross-sectional Setting: First Episode Clinic at Tohoku University Hospital, Japan.	N=104 Mean age: 22 39 males and 65 females	Physical QoL domain(s): Physical Measure: The World Health Organization Quality of Life Schedule Brief version (WHOQOL-BREF; The WHOQOL Group, 1998).	**Severity of depression** Definition: None Measure: The Beck Depression Inventory-II (BDI-II; Beck et al., 1996).	Severity of depression was negatively associated with the physical domain (r=-0.81, p<0.001).
Rayan et al., (2017)	Design: Cross-sectional Setting: Two large psychiatric outpatient clinics in Jordan.	N=160 Mean age: 31 82 males and 78 females	Physical QoL domain(s): Physical function, role physical, energy fatigue, and pain. Measure: The Short Form Health Survey (SF-36; Ware et al., 1992).	**Depressive symptoms** Definitions: None Measure: The Center for Epidemiologic Studies Scale (CES-D; Radloff, 1977).	Severity of depressive symptoms was positively associated with the following domains: physical function (r=-0.404, p<0.01), role physical (r=-0.565, p<0.01), energy fatigue (r=-0.664, p<0.01), and pain (r=-0.617, p<0.01).
Ulas et al., (2008)	Design: Cross-sectional Setting:	N=72 Mean age: 33 44 males and 28 females	Physical QoL domain(s): Physical Measure:	**Depressive symptoms** Definitions: None Measure:	Severity of depressive symptoms was negatively associated

Source	Methods	Sample	Physical QoL	Factors associated with physical QoL	Association between factors and physical QoL domains
	Inpatients and outpatients from psychiatry clinics of the Medical School of Dokuz Eylül University, Turkey.		The World Health Organization Quality of Life Schedule Brief version (WHOQOL-BREF; The WHOQOL Group, 1998).	The Calgary Depression Scale for Schizophrenia (CDSS; Addington and Schissel, 1990).	with the physical domain (r=-0.504, p<0.001).
Ulas et al., (2010)	Design: Cross-sectional Setting: Inpatients and outpatients from psychiatry clinics of the Medical School of Dokuz Eylül University, Turkey.	N=88 Mean age: 35 54 males and 34 females	Physical QoL domain(s): Physical Measure: The World Health Organization Quality of Life Schedule Brief version (WHOQOL-BREF; The WHOQOL Group, 1998).	**Depressive symptoms** Definitions: None Measure: The Calgary Depression Scale for Schizophrenia (CDSS; Addington and Schissel, 1990).	Depressive symptoms were negatively associated with the physical domain (r=-0.43, p<0.001).
Brissos et al., (2011)	Design: Cross-sectional Setting: Outpatients from 2 psychiatric departments in Lisbon, Portugal.	N=76 Mean age: 39 56 males and 20 females	Physical QoL domain(s): Physical Measure: The World Health Organization Quality of Life Assessment— Brief Form scale (WHOQOL-BREF; WHOQOL Group, 1998).	**Severity of depression** Definition: None Measure: Depression items from the Positive and Negative Syndrome Scale for Schizophrenia (PANSS; Kay et al., 1987).	Non-significant association between severity of depression and the physical domain (r=-0.202, p >= 0.05).
Vancampfort et al., (2015)	Design: Cross-sectional Setting: Inpatients of the University Psychiatric Centre,	N=47 Mean age: 33.8 34 males and 13 females	Physical QoL domain(s): Physical health Measure: Short Form Health Survey (SF-36; Ware et al., 1992).	**Depressive symptoms** Definition: No Measure: The Psychosis Evaluation Tool for Common Use by	Non-significant association between depressive symptoms and the physical domain (r=-0.27, p=0.1).

Source	Methods	Sample	Physical QoL	Factors associated with physical QoL	Association between factors and physical QoL domains
	KU Leuven, Belgium.			Caregivers (PECC; De Hert et al., 1998).	
Body mass index/obesity					
Bressington et al., (2016)	Design: Cross-sectional Setting: Outpatients from Community Psychiatric Service in Hong Kong, China.	N=82 Mean age: 48 49 males and 33 females	Physical QoL domain(s): Physical Measure: The 12-Item Short-Form Health Survey (SF12v2; Ware et al., 1996).	**BMI** Definition: None Measure: Not reported	BMI was negatively associated with the physical domain (r=-0.272, p=0.013).
Kolotkin et al., (2008)	Design: Cross-sectional Setting: Outpatients from 57 clinical sites in the United States.	N=111 Mean age: Not reported 98 males and 113 females	Physical QoL domain(s): Physical functioning, role functioning, bodily pain, vitality, and physical component. Measures: The Short Form Health Survey (SF-36; Ware et al., 1992).	**Obesity** Definition: Categorized as obese or non-obese (BMI of ≥30). Measure: Not reported	Obese patients had lower QoL in the following domains: physical functioning (p<0.001), role functioning (p<0.001), bodily pain (p<0.001), vitality (p=0.014), and physical component (p<0.001) compared with non-obese patients.
Sugawara et al., (2013)	Design: Cross-sectional Setting: Outpatients in Japan.	N=225 Mean age: 42 106 males and 119 females	Physical QoL domain(s): Physical functioning and physical composite score. Measure: The Short Form Health Survey (SF-36; Ware et al., 1992).	**Obesity** Definition: Categorized as normal weight (BMI <25), overweight (25< BMI<29.9), or obese (BMI> 30). Measure: Researcher-developed forms.	Obesity was negatively associated with the following domains physical functioning (β=-0.195, p<0.01) and physical composite score (β=-0.158, p<0.05).

Source	Methods	Sample	Physical QoL	Factors associated with physical QoL	Association between factors and physical QoL domains
Gomes et al., (2016)	Design: Cross-sectional Setting: Outpatients from psychiatric rehabilitation units, Brazil.	N=32 Mean age: 41 23 males and 9 females	Physical QoL domain(s): Physical Measure: The World Health Organization Quality of Life assessment— Brief Form scale (WHOQOL-BREF; WHOQOL Group, 1998).	**BMI** Definition: None Measure: Not reported.	BMI was negatively associated with the physical domain (r=-0.367, p=0.039).
Guo et al., (2013)	Design: Cross-sectional Setting: Early-stage Schizophrenia patients from 10 sites in China.	N=1108 Mean age: Underweight group (27), normal weight group (27.2), overweight group (28), and obese group (27). 603 males and 505 females.	Physical QoL domain(s): Physical functioning, role-physical, bodily pain, and physical component summary. Measure: The Short Form 36 Health Survey questionnaire-Mandarin version (SF-36; Ware et al. 1994).	**BMI** Definition: Based on the formula: weight in kilograms divided by height in meters-squared (kg/m 2). Measure: Categorized into underweight (< 18.5 kg/m 2), normal weight (18.5 – 22.9 kg/m 2), overweight (23 – 27.4 kg/m 2) and obesity (≥ 27.5 kg/m 2), using cut-offs for Asian populations recommended by the World Health Organization.	BMI was negatively associated with the following domains: physical functioning (r=-0.0077, p=0.01), role-physical (r=-0.0088, p=0.003), and physical component summary (r=-0.0083, p=0.006).
Kerling et al., (2013)	Design: Cross-sectional Setting: Psychiatric out-patient clinic of the Hannover Medical School.	N=31 Mean age: 34 18 males and 13 females	Physical QoL domain(s): Physical functioning Measures: The Short Form Health Survey (SF-36; Ware et al., 1992).	**BMI** Definition: None Measure: Not reported	BMI was negatively associated with the physical functioning domain (r=-0.53, p<0.01).

Source	**Methods**	**Sample**	**Physical QoL**	**Factors associated with physical QoL**	**Association between factors and physical QoL domains**
Vancampfort et al., (2011)	Design: Cross-sectional Setting: University Psychiatric Centre, Kortenberg in Belgium.	N=60 Mean age: 33 34 males and 13 females	Physical QoL domain(s): Physical and mental. Measure: The Short Form Health Survey (SF-36; Ware et al., 1992).	**BMI** Definition: None Measure: Weight was measured with SECA beam balance scale. Height was measured using a wall-mounted stadiometer.	Higher BMI was negatively associated with the physical domain (β=-0.53, p<0.001).
Vancampfort et al., (2015)	Design: Cross-sectional Setting: Inpatients of the University Psychiatric Centre, KU Leuven – University Leuven in Belgium.	N=47 Mean age: 33 34 males and 13 females	Physical QoL domain(s): Physical Measure: The Short Form Health Survey (SF-36; Ware et al., 1992).	**BMI** Definition: None Measure: Weight was measured with SECA beam balance scale. Height was measured using a wall-mounted stadiometer.	BMI was negatively associated with the physical domain (r=-0.30, p=0.004).
Physical activity					
Deenik et al., (2017)	Design: Cross-sectional Setting: Long-term inpatients from a psychiatric hospital, Netherlands.	N=184 Mean age: 57 108 males and 76 females	Physical QoL domain(s): Physical Measure: The World Health Organization Quality of Life assessment— Brief Form scale (WHOQOL-BREF; WHOQOL Group, 1998).	**Physical activity** Definition: Average total activity counts per hour. Measure: The ActiGraph GT3X+ (ActiGraph, Pensacola, Florida, VS).	Physical activity was positively associated with the physical domain (β=1.18, p<0.05).

Source	Methods	Sample	Physical QoL	Factors associated with physical QoL	Association between factors and physical QoL domains
Gomes et al., (2016)	Design: Cross-sectional Setting: Outpatients from psychiatric rehabilitation units, Brazil.	N=32 Mean age: 41 23 males and 9 females	Physical QoL domain(s): Physical Measure: The World Health Organization Quality of Life assessment— Brief Form scale (WHOQOL-BREF; WHOQOL Group, 1998).	**Physical activity** Definition: Frequency of physical activity. Categorized as sedentary, light, moderate, vigorous. or most vigorous. Measure: The GT3X triaxial accelerometer (Actigraph, Florida) in (min/day).	Light physical activity was negatively associated with the physical domain (r=-0.436, p=0.013).
Heggelund et al., (2011)	Design: Cross-sectional Setting: Inpatients and outpatients, Norway.	N=33 Mean age: Males (33) and females (35) 22 males and 11 females	Physical QoL domain(s): Physical functioning, vitality, and physical component summary. Measures: The Short Form Health Survey (SF-36; Ware et al., 1992).	**Peak oxygen uptake** Definition: The highest oxygen uptake (ml·kg-0.75·min-1) recorded during the last minute of a treadmill test. Measure: The Metamax II portable metabolic test system (Cortex Biophysik GmbH, Leipzig, Germany).	Peak oxygen uptake was positively associated with the following domains: physical functioning (r=0.58, p<0.001), vitality (r=0.47, p<0.05), and physical component summary (r=0.51, p=0.005).
Vancampfort et al., (2015)	Design: Cross-sectional Setting: Inpatients of the University Psychiatric Centre, KU Leuven – University Leuven in Belgium.	N=47 Mean age: 33 34 males and 13 females	Physical QoL domain(s): Physical Measure: The Short Form Health Survey (SF-36; Ware et al., 1992).	**Aerobic fitness** Definition: Maximal oxygen uptake. Measure: With submaximal Astrand–Rhyming cycle ergometer test.	Higher levels of aerobic fitness were positively associated with the physical domain (r=0.57, p<0.001).

Source	**Methods**	**Sample**	**Physical QoL**	**Factors associated with physical QoL**	**Association between factors and physical QoL domains**
Vancampfort et al., (2011)	Design: Cross-sectional Setting: University Psychiatric Centre, Kortenberg in Belgium.	N=60 Mean age: 33 34 males and 13 females	Physical QoL domain(s): Physical and mental. Measure: The Short Form Health Survey (SF-36; Ware et al., 1992).	**Leisure time physical activity** Definition: None Measure: The Baecke Physical Activity Questionnaire (Baecke et al., 1982) **Functional exercise capacity** Definition: None Measure: The 6MWT test (Vancampfort et al., 2010).	Leisure time physical activity was positively associated with the physical domain (β=0.48, p<0.001). Functional exercise capacity was positively associated with the physical domain (β=0.43, p<0.001).

Note. Non-significant findings are highlighted in grey.

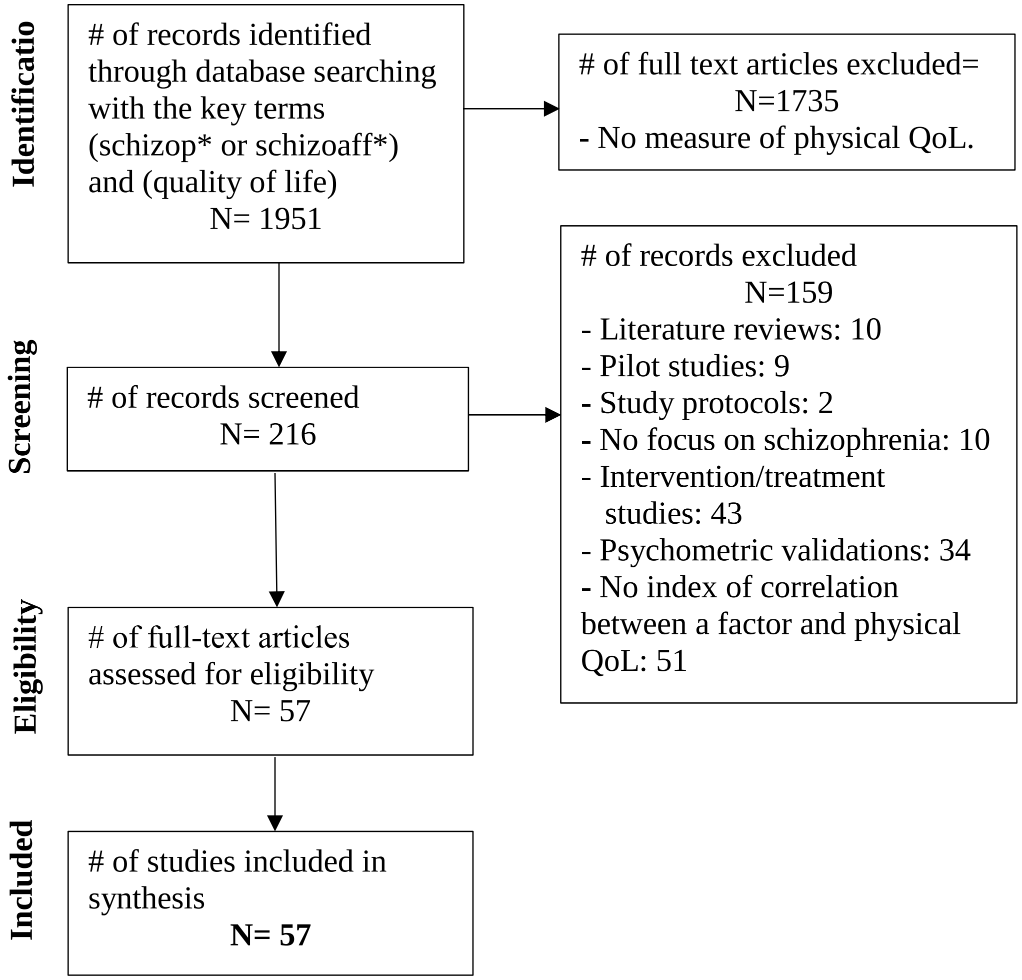

Figure 2.1. PRISMA Diagram (Moher et al., 2009)

CHAPTER 3

Chapter 3 describes a qualitative descriptive study conducted to describe common HRQoL concerns in people with schizophrenia based on narratives in which they describe their life experiences.

Introduction

Schizophrenia is a serious mental illness that significantly lessens the health-related quality of life (HRQoL) of those who suffer from the illness (Barnes et al., 2012; Vancampfort, et al., 2015). HRQoL includes persons' positive and negative evaluations of any aspects of their everyday lives that are influenced by disease- or health-related factors (Barnes, Murphy, Fowler & Rempfer, 2012; Chan, Hsiung, Thompson, Chen & Hwu, 2007). HRQoL in people with schizophrenia would thus include their sense of well-being and satisfaction with life in the context of their illness. In order to provide comprehensive and integrated care for people with schizophrenia, it is critical to understand how they experience their HRQoL. This understanding can be gleaned from attending to how they describe their daily lives in their own words.

A number of aspects of the illness can contribute to lowered HRQoL in people with schizophrenia. The symptoms and cognitive dysfunction resulting from schizophrenia can have a devastating impact on one's daily functioning and sense of well-being (Barnes et al, 2012; WHO, 2016). In addition, people with schizophrenia experience a number of challenges that also affect their welfare. They experience stigma and social isolation, have limited life and employment opportunities (Bouwmans, De Sonneville, Mulder & Hakkaart-van Roijen, 2015; Kelly, 2005), suffer high rates of physical comorbidities, such as cardiovascular disease (Correll, Ng-Mak, Stafkey-Mailey, Farrelly & Loebel, 2017; Jones et al., 2004; Muir-Cochrane, Cleary, Walter & Matheson, 2008; Nishanth, Chadda, Sood, Biswas & Lakshmy, 2017), and often experience psychiatric comorbidities, such as depression and substance abuse (Bridgman, Ouellet-Plamondon, Morozova & George, 2013). The destructive impact of schizophrenia on everyday lives of people with schizophrenia is reflected in a life expectancy that is two decades shorter than the general population (De Hert et al., 2011; Foldemo et al., 2014; Moore, Shiers, Daly, Mitchell, & Gaughran, 2015).

Most studies investigating HRQoL in people with schizophrenia have identified discrete measurable factors that either detract from or contribute to their HRQoL. Illness-related factors that have been shown to diminish HRQoL in this population include poor overall mental health (Chan et al., 2007), the severity of negative or psychotic symptoms (Barnes et al., 2012; Thornicroft et al., 2004), co-morbid depression and anxiety (Barnes et al., 2012; Thornicroft et al., 2004), co-morbid drug use (Kerfoot et al., 2011), and the severity of side effects from antipsychotic medications (Ritsner, Arbitman, Lisker & Ponizovsky, 2012). Daily challenges associated with lower HRQoL include low participation in leisure time physical activities (Vancampfort et al., 2011), homelessness (Anquier et al., 2013), and unemployment (Thornicroft et al., 2004). llness-related factors that have been shown to be associated with higher HRQoL include fewer cognitive symptoms (Vancampfort et al., 2015), less medical comorbidity (Barnes et al., 2012), and more effective medication management (Montgomery, Kadziola, Ye, Xue & Truer, 2015). Social factors associated with higher HRQoL include social support (Ho et al., 2010) and social integration (Meijer, Koeter, Sprangers & Schene, 2009). Intrapersonal factors associated with higher HRQoL include higher levels of self-esteem, self-efficacy (Meijer et al., 2009; Nakamura, Watanabe & Matsushima, 2014; Ritsner et al., 2012), personal agency, resilience, sense of optimism, and happiness (Ho, Chiu, Lo & Yiu, 2010; Palmer, Martin, Depp, Glorioso & Jeste, 2014) as well as lower levels of internal stigma (Ho et al., 2010).

Although these quantitative studies are helpful to provide evidence of associations between a multitude of factors and HRQoL, they fail to provide an in-depth description of HRQoL in people with schizophrenia. Some qualitative studies have explored topics that are related to HRQoL in this population, such as feelings of loss and coping (Mauritz & Meijel, 2009), challenges related to negative symptoms (Pai & Vella, 2015), the meaning and importance of employment (Dunn, Wewiorski & Rogers, 2008), and the importance of religion and spirituality in life goals (Huguelet, Mohr, & Borras, 2009). However, few qualitative studies have explored more broadly the HRQoL issues that are of most concern to people with schizophrenia. In order to develop more comprehensive treatment strategies to improve the overall welfare of people with schizophrenia, it is important to identify and describe these concerns.

The purpose of this study is to describe common HRQoL concerns in people with schizophrenia based on narratives in which they describe their life experiences. Because qualitative research is based on the assumption that meaning exists within human subjectivity, and persons’ narrative descriptions of their lived experiences provide a robust glimpse into what most concerns them (Munhal, 2012), qualitative methods were deemed to be best suited for this study. The qualitative approach will provide an in-depth understanding of persons’ HRQoL concerns within the context of their day-to-day lives by exploring the complex, contextual, and interconnected ways in which their illness influences their well-being.

Methods

Qualitative descriptive methods as described by Sandelowski (2000) guided the study. The goal of qualitative description is to use low interpretive inductive analyses to provide a coherent and useful summary of events. Qualitative description is the preferred method to provide a straightforward description of phenomena in a manner that is relevant to practitioners and policy makers. Qualitative content analysis is the analytic strategy used most frequently in qualitative descriptive approaches (Sandelowski, 2000). Because the goal of the current study was to provide a clear description of common HRQoL concerns as revealed by people with schizophrenia, qualitative description was deemed to be the most appropriate method. Data for this study were drawn from a larger study referred to as the parent study as described in Chapter 1.

Current Study

The current study focused on participants from the serious mental illness group. All had been diagnosed with schizophrenia or schizoaffective disorder. The IPII narratives, which were transcribed and checked for accuracy, provided data for the current study. The primary investigator ascertained that the IPII narratives contained rich information about the participants' perceptions of their HRQoL and therefore provided ample data to meet the study aims.

Data Analysis

The participant narratives were analyzed with conventional content analysis as described by Miles, Huberman & Saldaña (2014). The analysis team included the primary investigator, a doctoral candidate in nursing, a senior nurse scientist with expertise in qualitative methods; and a senior nurse scientist with expertise in schizophrenia. Because the interviews covered a broad range of topics, and we wished to specifically address HRQoL concerns, the analysis focused on concerns that the participants' expressed in regard to how their illness influenced their everyday functioning or well-being (hereafter referred to as "concerns"). Descriptions of positive experiences that counteracted or ameliorated the concerns were coded as well. Other topics covered in the interview, such as the participants' life or treatment histories, were considered for context but were not included in the analysis if participants did not connect these experiences to the quality of their current everyday lives. The data were analyzed in several steps.

Step 1: To get an overall sense of the experiences of the participants, the primary investigator read through the transcripts several times and recorded his initial impressions of the participants' concerns. Step 2: The primary investigator highlighted and extracted all text units (e.g., words, phrases, or sentences) that reflected a concern as described above. Step 3: The primary investigator coded each of the text units with a word or short phrase that reflected its meaning or essence. A second team member, the expert in qualitative research, reviewed the coding of the text units. Step 4: With input from this team member, the primary investigator compared the codes for similarities and differences and divided the codes into four common categories representing four broad areas of concerns. Step 5: A person-by-topic matrix (Miles et al., 2014) was developed to organize and display the text units. The four categories were placed on the horizontal axis and a code number represented each participant was placed on the vertical axis. Text units were placed in the appropriate cell (e.g., participant 13007 X concerns about interpersonal relationships) by the primary investigator. The primary investigator, with input from team members, divided the text units in each column into sub-categories reflecting the dimensions of each category. Step 6: The primary investigator constructed a topic-by-category-matrix (Miles et al., 2014) that displayed the codes that comprised each category and subcategory with links to relevant data in the transcripts. Step 7: The primary investigator, developed narrative descriptions of each category and sub-category. Step 8: The primary investigator presented the categories and subcategories, the narratives descriptions, and supporting data to the research team to obtain feedback on the relevancy of the categories and the extent to which they reflected the data. Revisions were made to the narratives by the primary investigator.

Trustworthiness

According to Lincoln and Guba (1985), establishing trustworthiness in qualitative work involves using strategies to ensure that the findings are well-grounded in the data and could be confirmed by others following similar procedures. To ensure trustworthiness of the findings of this study, two procedures were followed. First, peer debriefing was used throughout the process through frequent team meetings to ensure consensual validity for each analytic decision made. Second, the primary investigator maintained an audit trail that reflected all methodological and analytic decisions made during the course of the study.

Findings

Sample

The sample included 17 men and 3 women. All had been diagnosed with schizophrenia or schizoaffective disorder. Nine participants identified as Black or African American, 6 as Caucasian, 2 as multiracial, and 3 as unknown race. Participants ranged in age from 24 years to 60 years. Some demographic data, such as age, were missing for some participants.

The primary investigator determined that the HRQoL concerns expressed by the participants could be divided into four main categories as follows: social relationships, psychiatric symptoms, psychiatric care, and employment. For each category, there were a number of subcategories. The four categories and the sub-categories are described in the following sections and examples and verbatim quotes from the transcripts are provided.

Concerns Related to Social Relationships

All participants expressed concerns about their social relationships. The participants indicated that the lack of relationships, or relationships that were conflictual or deficient in some way, detracted from their sense of well-being, whereas relationships that provided companionship, passion, or support contributed to it. Participants talked about relationships with romantic partners, family members, friends, and strangers.

Romantic relationships. Seventeen participants described concerns about relationships with romantic partners. Some felt deprived of romantic relationships due to their mental illness. They felt others did not “want” them romantically because their symptoms were off-putting, their behaviors were distressing or even dangerous to others, they experienced sexual dysfunctions, or they were generally unworthy. A 60-year-old man said, “There ain’t too many girls that want to get involved with somebody like me.” Others believed that they lacked romantic relationships because they did not have the skills to engage with potential partners or know how to “read signals” that another person might be interested in them. A woman (age unknown) stated, “I just don’t know what to do… I worry about what to say.” Many participants worried about spending the rest of their lives alone, and several longed to find a partner or to feel passion, which they believed would allow them to have a better life.

The few participants who were engaged in a romantic relationship noted that their partners kept them from being alone and brought them happiness. A 46-year-old man explained that human beings were “social creatures” meant to “flock together.”

Family relationships. Sixteen participants described concerns relative to their family relationships. Many participants reported being estranged from their families. Some had little or no contact with their families-of-origin, and the participants felt abandoned, ignored, or merely tolerated by family members. A 60-year-old man describing the impact of mental illness on his family relationships said, “It took… my humanity away... It made me worse as far as trying to be a human with a relationship with my mother, my daddy, my brothers… They were at the point where…they used to hate to see me coming.” In some instances, family members had other responsibilities that precluded them from attending to the needs of the participants, and the participants resented this. Others had been separated or divorced from spouses or had given up or lost their children, which left many feeling lonely and regretful. Almost all the participants who felt estranged from their families attributed the estrangement to the participants' illness.

When participants did have relationships with family members, they were often conflictual. Some participants described fights, arguments, and even violent altercations with family members. Participants often argued with family members over "basic things." A man (age unknown) said that he had "a lot of arguments" with his wife over money, child rearing, his inappropriate behaviors, and his being unavailable when his family needed him. A few participants were suspicious of their family members and felt they had taken advantage of the participants or stole their money. Several participants were troubled because they felt like a burden to their family members and depended on them to meet basic needs.

The few participants who still had meaningful family relationships acknowledged that those relationships provided guidance, love, and motivation to do well. A 41-year-old woman said, "I've got one son…he…gives me a reason to stay doing right."

Friendships. Fourteen participants described concerns relative to their relationships with friends. Many of these participants felt deprived of meaningful friendships in their lives. A 60-year-old male said, "I don't feel that I can exactly have a friend, a good close dear friend to rely on." Some had lost friends because the friends had problems with drugs or mental illness themselves, and others could not make friends because the participants were distrustful of others or because their mental illness made it challenging to establish friendships. A 32-year-old man noted that one-by-one his ties with friends were "cut off" and that he never saw them again. Some participants felt that friends took advantage of them. A woman (unknown age) said, “They wouldn’t even want to…talk to me on the phone…They’re trying to milk me out of my money.”

The few participants who managed to maintain meaningful friendships felt “blessed” to have people they could count on and who would “go out of their way” to provide support. A 52-year-old woman who had a friend who also had a mental illness felt that they were like “two peas in a pod.” She said, “He helps me. I help him…He doesn’t live with me. He’s just my friend.”

Interactions with strangers. Seventeen participants described concerns relative to their interactions with strangers. They felt distressed when strangers “made fun” of the participants, harassed them, called them names, and threatened them. A man (unknown age) felt that he could not “let his guard down” because people were “preying” on him. Others recognized that their behaviors toward strangers, such as talking very loudly, being mean, “going off snapping,” and getting upset in public, could be troubling and disruptive. A man (unknown age) said, “I start speaking out loud and it scares them. It’s like shining a flash light on a vampire.” Several participants had developed techniques that helped avoid aversive interactions with strangers when they were “out in public” including withdrawing before a confrontation ensued, informing others about their mental illness, interacting with others only for a short time, seeking out “nice” people, and trying not to worry about what others think.

Even though interactions with strangers were usually challenging, some participants valued encounters that went well. A 46-year-old man said, “I believe human interaction is the most precious thing there is… a life isn’t worth living if you don’t touch someone else’s life.”

Concerns Related to Psychiatric Symptoms

Nineteen participants expressed concerns about the psychiatric symptoms they experienced. They experienced a wide variety of symptoms, which most believed affected their well-being and everyday functioning in significant ways. The troublesome symptoms described by the participants fell into the established categories of positive, negative, and cognitive symptoms.

Positive symptoms. Fourteen participants described concerns related to symptoms that could be classified as positive symptoms. Many participants experienced frightening or disturbing thoughts. They believed that they were being watched, monitored, or controlled by outside forces; they were surrounded by evil; and their lives were in danger. Several "heard voices," which were most often threatening, and one participant saw "dead people." The symptoms profoundly impinged upon everyday lives. They experienced these symptoms as "harrowing;" many had to remain vigilant and seldom found peace. A woman (unknown age), for example, blocked her doors and windows at night because she was convinced people were going to kill her. Often the participants withdrew from others to avoid alarming them with their symptoms or to prevent other persons or forces from harming them. In several instances, the symptoms lead to the participants being hospitalized or incarcerated. The symptoms also caused the participants self-doubt as they could not distinguish their symptoms from reality. A woman (unknown age) said, "Sometimes … just [to] distinguish the real from the non-real… It's one of my major problems." The participants typically tried to ignore their "evil" thoughts or to not act on them. Many felt they had little control over these symptoms, whereas a few learned to ignore voices and troublesome visions. A 46-year-old man said, “My life is a lot better when I learn to not care about what the shadows are doing.”

Negative symptoms. Eleven participants described concerns related to negative symptoms. Several talked about not experiencing emotions, lacking motivation or ambition, having little energy, and not experiencing pleasure. These experiences affected their day-to-day lives as they found it difficult to do things and could not “get excited” by life anymore. Most of these participants attributed these experiences to their illness, and several compared their current lives to what they used to be like before they became ill or when they “were young.” A 60-year-old man said, “I just … don’t have that gusto for life anymore as much as I used to before I got sick.”

Cognitive symptoms. Ten participants described concerns related to their cognitive symptoms, especially memory and attention. Many of these participants were concerned about not being able to remember past events, and this troubled them a great deal. A 48-year-old man stated that memory problems “can ruin one’s life if you cannot remember what you have done,” another lamented his memories were “locked in the past” and “washed out of his life,” and another bemoaned that he would no longer be able to tell his life story. Cognitive problems could also affect day-to-day functioning in practical ways. Some participants could not remember to take their medications, and others could not concentrate enough to work, read, accomplish tasks, or move from one project to another. A 59-year-old man said these problems made him “feel stupid.”

Concerns Related to Psychiatric Care

Eighteen participants expressed concerns about the psychiatric care they received. They were troubled by the medications they were prescribed, the hospitalizations they had to go through, and the relationships they had with health care providers.

Medications. Eleven participants described concerns about the medications they were prescribed. A common concern about medications stemmed from the side effects. Some participants described impotence and sterility, sedation, impaired speech, personality changes, and allergic reactions that they attributed to the medication. A man (unknown age) said, "They had me on some medication… made me impotent where I couldn't perform sexually…this ain't what my life's supposed to be." Other participants did not believe their medications were effective. Several found the medicine prescribed for them "did not work" or that it took some time for their providers to find a medication that was effective. Some hoped to "get off medicine" in order to "be normal" again, but others realized that they would be on medication for life and lamented that the medication would not "cure" schizophrenia.

Some of the participants recognized the benefits of medications. They acknowledged that medications helped relieve their hallucinations, calm their anxiety, and control their "anger bursts." These participants appreciated that medications helped them be productive, live in the community, and avoid jail. A woman (unknown age) felt relieved because she could control "all that anger" by taking her medicine. A few participants noted that to obtain these benefits, it was important to get the "right medicine" and to know how to take it.

Hospitalization. Fourteen participants expressed concerns about being hospitalized. Some participants felt that being hospitalized negatively impacted their lives, whereas other participants acknowledged that hospital stays provided an opportunity to improve their lives. A few resented going to hospitals because these facilities were for “abnormal” people. Some believed that the more they could stay out of the hospital, the better they were doing. A 60-year-old man said, “I guess I must be doing kind of all right. I have not been hospitalized in…12 years.” A 24-year-old man said, “I want to… work my way out of being a [mental health clinic name] patient and just try to be a normal person.”

Some participants on the other hand appreciated the services and opportunities offered by hospitals. One 52-year-old woman stated that the hospital was “the best thing” that happened to her. A 59-year-old man believed it was good to go to the hospital when his health was “taking a turn for the worse.” For some participants, being in the hospital afforded them opportunities to learn about their illness, develop coping skills, relax and socialize, obtain referrals for providers, benefit from group therapy, and access training opportunities.

Relationships with health care providers. Nine participants expressed concerns about their relationships with health care providers. Some participants were not satisfied with the quality of the relationship and the services provided by health care providers, which they felt negatively impacted their lives. Some did not get enough information from their providers about medication side effects, felt misunderstood by them, had a passive role in the relationship with providers, and had providers who failed to address some of their symptoms. A woman (unknown age) describing her relationship with health care providers in a mental health clinic said, “Nobody…understood me… Nobody cared.”

Some participants were satisfied with the relationship they had with their providers and valued their guidance. These participants appreciated getting information about their treatments, being taught skills to help control their symptoms, and getting help to set goals and stay “on track.” A 60-year-old said, “I see [Doctor‘s name] every two weeks…he…keeps track of me. He helps me.”

Concerns Related to Employment

Nineteen participants expressed concerns relative to employment issues. While most felt that difficulties getting jobs, maintaining employment, or interacting with co-workers detracted from their sense of well-being and functioning, a few described employment experiences that brought them satisfaction.

Difficulty getting or maintaining employment. Ten participants described difficulties obtaining or maintaining employment. Some simply indicated that they no longer worked because of their illness and had come to terms with this. Others indicated that employment problems negatively affected their lives. They complained that it was “hard to get a job” and their illness limited their opportunities. A few who were working at the time of the interview worried about losing their jobs because of their symptoms; they felt like “a mess” at work, were forgetful and unable to concentrate, and believed their performances had “slipped.” Some participants felt that the medications they took made them sluggish at work; a man (unknown age) stated that he was “always in slow motion.” Several were fired for these reasons and felt like they were always looking for new jobs. A man (unknown age) said, "That's the problem that I go through here in life… I can't keep a job."

Interpersonal conflicts in the workplace. Eleven participants described interpersonal conflicts at work. Many participants had problems with co-workers or supervisors. These participants became irritable with others, confronted others for perceived maltreatment, got into physical altercations, resisted being told what to do, and shared their delusional thoughts, which upset co-workers. Some attributed these problems to unreasonable co-workers, whereas others recognized that their illness was the root of their interpersonal difficulties at work. A 60-year-old man who believed co-workers triggered the conflicts at work said, "I don't know how many … offices I… tore up. So yeah, I let them push the button on me."

Benefits/satisfaction from work. A few participants who were employed felt "proud" and "happy and excited" about their jobs. Some acknowledged aspects of their jobs that helped them be successful at work, including work accommodations to limit the impact of medication side effects, a structured environment, part-time work, flexible hours, and being able to work alone. A woman (age unknown) who was dizzy because of her medication appreciated that her boss was able "to accommodate" her deficits by letting her use a stool rather than standing.

Many participants who were currently unemployed reminisced about past employment experiences. Some acknowledged that work brought them joy, allowed them to interact with interesting co-workers, and provided an opportunity to save money and travel. Many unemployed participants hoped or expected to get a job in the future to become "a productive person," be independent, and "have a better life."

Other HRQoL Concerns

Beyond the main concerns described, a few participants also mentioned other concerns that affected their day-to-day lives but were not described sufficiently to warrant a separate category. A few worried about their mental and physical comorbidities, poverty, issues with the law, past traumas, and uncertainty about the future. Conversely, others acknowledged that spirituality, the use of self-management strategies, having a positive disposition toward life, and having a sense of control represented opportunities to improve their lives.

Discussion

In the life narrative interviews, the participants indicated that problematic social relationships, troubling psychiatric symptoms, problems related to their psychiatric care, and limitations in employment were most likely to affect their HRQoL. Sometimes the participants' concerns caused considerable distress for them, whereas other concerns were bothersome but tolerable. Most participants were clear that their concerns were rooted in the nature of their illness, whereas a few attributed their troubles to other people who mistreated them or a healthcare system that failed to cure them. Our findings thus indicate that schizophrenia can have a profound impact on the HRQoL of people with the illness as the participants provided robust examples of the ways that schizophrenia had affected their well-being and functioning in several areas of their lives. While participants primarily discussed how their illness negatively affected their well-being, several discussed factors that counteracted these effects including supportive others, their own resilience, and good psychiatric care.

The weight that our participants gave to concerns about social relationships is consistent with the findings of a number of prior studies. A qualitative study of people with schizophrenia based on six interviews with persons suffering from the illness (Gee, Pearce & Jackson, 2003), for example, revealed that “barriers placed on interpersonal relationships” (p. 6) was one of ten domains identified as being important to the quality of life by the study participants. Similarly, our finding that participants experienced loneliness and regret about having lost their nuclear families due to their illness is consistent with studies that revealed people with schizophrenia who were married (Akinsulore et al., 2014; Othman et al., 2013) and had children (Batista de Freitas et al., 2016) had a higher HRQoL than those who did not. Our findings that participants lamented being spurned by romantic partners, castoff by family members, rejected by coworkers, and disparaged by strangers because of their illness supports previous study findings that social stigma is associated with lower HRQoL (Chou et al., 2014), whereas social support from friends and patient-peers is associated with higher HRQoL (Ho et al., 2010).

Our finding that psychiatric symptoms interfere with the everyday lives of people with schizophrenia in profound ways is also consistent with prior study findings. In the qualitative study of mentioned above (Gee et al., 2003), for example, “subjective experience of psychotic symptoms” (p. 7) was one of the ten domains identified as important to the participants’ quality of life. Moreover, numerous quantitative studies have found the presence or severity of positive (Rofail et al., 2015; Vancampfort et al., 2015), negative (Barnes et al., 2012; Ritsner et al., 2012), and cognitive (Vancampfort et al., 2015) symptoms are associated with lower HRQoL.

The concerns our participants expressed regarding a variety of aspects of their psychiatric care were also found in prior study findings. For example, quantitative studies have revealed that the severity of medication side effects (Rofail et al., 2015; Vancampfort et al., 2015) and the number of previous hospitalizations (Ritsner et al., 2012) were associated with lower HRQoL in this population. Our finding that relationships with health care providers affect HRQoL has also been discussed in the literature. For example, studies have found that autonomy support from clinicians (Ho et al., 2010) and empowering interventions by nurses that promote self-determination are associated with higher patient QoL (Pitkänen, Hätönen, Kuosmanen & Välimäki, 2008).

Our finding that employment issues created significant concerns for our participants supports prior research as well. In the qualitative study mentioned above (Gee et al., 2003), the "loss of opportunity to fulfill occupational roles" (p. 6) was identified as one of the important domains of quality of life. Moreover, studies have shown that in people with schizophrenia being employed is associated with higher HRQoL (Akinsulore et al., 2014; Caqueo-Urízar et al., 2016; Chou et al., 2014; Othman et al., 2013).

Although our findings confirm much prior work on HRQoL in people with schizophrenia, our study extends this body of literature by providing a more nuanced and complex understanding of how people with schizophrenia experience the threats to their HRQoL stemming from their illness. For example, while prior research substantiates that interpersonal ties, social integration, and social support are significantly related to HRQoL, our description of concerns related to social relationships captures in an in-depth manner the participants longing for romantic ties, the multiple ways in which family estrangement and conflict pervade their lives, the void they feel by not having friends, and the angst they experience from interactions with total strangers. Similarly, while prior research shows that positive, negative, and cognitive symptoms are significantly associated with lower HRQoL, our findings provide a rich description of how these symptoms affect the participants everyday lives from their own perspectives. Some participants vividly described how their positive symptoms robbed them of any peace; their negative symptoms robbed them of ambition, pleasure, and energy; and their cognitive symptoms threaten to rob them of their life memories. Moreover, while prior research substantiates that severity of medication side effects, number of hospitalizations, and quality of relationships with health care providers are significantly related to HRQoL in this population, our findings bring to light how people with schizophrenia grant meaning to these experiences. The medication and its side effects signaled to the participants that they would never be normal and how frequently they were hospitalized signed how well they were doing. In addition, feeling heard and understood by their providers was experienced as a lifeline and being granted autonomy in their care provided a sense of worth. Likewise, while prior research showed significant associations with being employed and HRQoL, the participants' stories revealed what it is like to struggle to find employment, how hard it can be to maintain it, and what accommodations might enable success on the job.

The findings of the current study must be considered in the context of its limitations. The main limitation is that the interviews were conducted for the purposes of the larger parent study rather than to specifically explore the participants' HRQoL. The data were comprised solely of participant responses to the semi-structured Psychiatric

Illness Interview (IPII) (Lysaker et al., 2002). Although the primary investigator ascertained that the extant participant narratives contained enough rich information to meet the aim of the study reported here, he was unable to ask participants follow-up or clarifying questions about their HRQoL. As a result, some of the categories may have been incompletely described, and it is possible that some HRQoL concerns might not have been revealed in enough detail to constitute a category. The ability to probe further when participants mentioned any HRQoL topic might have allowed us to develop categories reflecting concerns that either participants mentioned only briefly or that they did not tie to their current life situations. For example, the participants discussed in some depth aversive experiences from earlier in their lives. Although we surmised ties between earlier life experiences and the participants' current well-being and functioning, there was little data to tie these experiences to the participants' present life circumstances. In addition, a larger sample might have allowed us to determine some associations between demographic and illness variables and the participants subjective evaluations of their daily lives. For example, there were only three women in the sample and thus we could not explore gender-specific factors that might influence HRQoL. We also did not have enough data to explore issues such as whether the severity of psychiatric symptoms or remission status of the participants would affect their HRQoL in meaningful ways. Finally, the IPII (Lysaker et al., 2002) was conducted at one point in time so we could not explore how participants' perceptions of their functioning and well-being might have changed over time. Thus, we recommend future longitudinal studies that use open-ended interviews to more fully explore HRQoL with larger and more diverse samples of people with schizophrenia as their illness unfolds.

Despite the study limitations, several clinical implications can be suggested. In addition to standard psychiatric assessments, clients with schizophrenia should be provided opportunities to discuss those concerns that arise in their everyday lives that are most salient to them. The categories identified here might serve as a starting springboard to provide an opportunity for clients to discuss what bothers or worries them most in these four domains. Many of the participants in this study embraced the opportunity to discuss struggles and regrets about their social relationships, ways their symptoms or treatments interfered with mundane daily tasks, how their relationships with health care providers might be better, and what they needed to hold down a job. While symptom management should remain a central feature of treatment for people with schizophrenia, strategies that help clients address the HRQoL concerns that are most important to them could improve their overall welfare, which in turn could facilitate the management of their illness.

Conclusion

Based on participants' own words, the findings of this study suggest that people with schizophrenia are most concerned about their social relationships, their psychiatric symptoms, their psychiatric care, and employment. Many were able to clearly articulate how their illness infringes on their daily sense of well-being and their functioning. While many studies have been conducted that examine the associations among a variety of factors and HRQoL in this population, more work needs to be done to understand HRQoL from the perspectives of persons who are burdened by the illness. Clinicians should initiate discussions with clients with schizophrenia about what troubles them most in their day-to-day lives and how they customarily confront these challenges. Holistic approaches to care call for an increased focus on clients' overall welfare that extends beyond symptom management.

CHAPTER 4

Chapter 4 describes a mixed methods study conducted to explore whether computerized lexical analysis on life narratives of people with schizophrenia can reveal their HRQoL concerns.

Introduction

The assessment of the health-related quality of life (HRQoL) in people with schizophrenia is important for research (Barnes, Murphy, Fowler & Rempfer, 2012; Vancampfort et al., 2015) and clinical practice (Powe, 2016; Wu, Kharrazi, Boulware, & Snyder, 2013). Schizophrenia is a serious mental illness that significantly lessens HRQoL (Barnes et al., 2012; Vancampfort et al., 2015). One approach to assessing HRQoL concerns in people with schizophrenia could be computerized lexical analysis. Computerized lexical analysis, an automatized process to count words in text data and sort them into pre-defined word categories, is based on the understanding that the words that people use when they communicate reflect thoughts, feelings, and concerns that are important to them (Tausczik & Pennebaker, 2010). This approach can thus capture internal states that persons might not otherwise be able to articulate (Minor et al., 2015) and might offer a viable strategy to identify the HRQoL concerns most salient to people with schizophrenia (Higginson & Carr, 2001; Michel et al., 2018).

Evaluating HRQoL in people with schizophrenia is complex as the illness can pervasively affect one’s sense of well-being in many domains and is affected by a variety of factors. According to Healthy People 2020, HRQoL is “a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning. It goes beyond direct measures of population health, life expectancy, and causes of death, and focuses on the impact health status has on quality of life" (p. 1). The HRQoL in people with schizophrenia can be negatively affected by the severity of their symptoms (Barnes et al., 2012; Thornicroft et al., 2004; Vancampfort et al., 2015), social isolation (Bouwmans, De Sonneville, Mulder & Hakkaart-van Roijen, 2015; Kelly, 2005), and unemployment (Thornicroft et al., 2004) and can be bolstered by effective medication management (Montgomery, Kadziola, Ye, Xue & Truer, 2015), social support (Ho et al., 2010), and social integration (Meijer, Koeter, Sprangers & Schene, 2009).

A convenient strategy for comprehensively and efficiently assessing HRQoL in people with schizophrenia could be of use in clinical practice. While symptom management is an important aspect of the treatment of people with schizophrenia, holistic and patient-centered approaches focus on HRQoL as well (Nakamura, Watanabe & Matsushima, 2014). These approaches require information about what aspects of their patients' lives are most affected by their illness and cause them the greatest concern. Such information can be used to inform treatment decisions, prioritize care, and improve patient outcomes (Guyatt et al., 2007; Higginson et al., 2001).

Methods currently used to measure HRQoL have several limitations and are challenging to implement in clinical practice (Awad & Voruganti, 2012; Boyer et al., 2013; Michel et al., 2018). Some standard paper-based questionnaires that measure HRQoL have been developed, including the Short Form Health Survey (SF-36; Ware et al., 1993) and the Schizophrenia Quality of Life Questionnaire (SQoL18; Boyer et al., 2010). However, these questionnaires are time-consuming for clients to complete, must be scored by clinicians, and provide only summary scores of HRQoL or its dimensions (Boyer et al., 2013; Michel et al., 2018). Moreover, these questionnaires do not provide information about patients' most relevant concerns in the context of their daily lives (Mitchel et al., 2018).

An alternative to using standard HRQoL questionnaires is conducting open-ended interviews in which people with schizophrenia are asked to discuss the aspects of their lives affected by their illness. Such interviews can provide an in-depth description of persons' HRQoL concerns within the context of their day-to-day lives and reveal the complex, contextual, and interconnected ways in which their illness influences their well-being. In a recent qualitative study conducted by the primary investigator, for example, illness narratives of people with schizophrenia revealed that participants were most concerned about their social relationships, psychiatric symptoms, psychiatric care, and employment. However, the analysis of open-ended interviews can be time-consuming and requires advanced analytic skills. Moreover, such approaches do not have well-established methods to address the disorganized thinking, reduced insight and impaired cognition that are common in the illness of people with schizophrenia (Zhou et al., 2015).

The use of computerized lexical analysis to assess HRQoL in people with schizophrenia could address the limitations of standard questionnaires and open-ended interviews by offering an efficient and objective way to assess HRQoL based on persons' own words. Computerized lexical analysis has been used successfully in research with this population to assess several factors. For example, computerized lexical analysis was used to demonstrate that compared to the general population, people with schizophrenia use more negative affect words (Fineberg et al., 2016) and more sadness words (Minor et al., 2015). Moreover, studies using computerized lexical analysis have also demonstrated that in people with schizophrenia more anger words are related to lower functioning and more severe reality distortion, and fewer social words are related to more negative symptoms (Minor et al., 2015). We thus hypothesized that because computerized lexical analysis can examine a large amount of text data efficiently and identify how frequently topics are represented in a narrative (Junghaenel, Smyth & Santner, 2008; Lowe, 2002; Pennebaker, Mehl, & Niederhoffer, 2003), it may also be useful for identifying HRQoL topics that are most concerning for people with schizophrenia.

Computerized lexical analysis has not yet been used to measure HRQoL concerns in people with schizophrenia. The purpose of the study, therefore, was to explore whether computerized lexical analysis of life narratives of people with schizophrenia could reveal their HRQoL concerns. A first step was to determine if the results of a computerized lexical analysis yielded findings that were similar to a more traditional content analysis of illness narratives. The convergence of the findings of the qualitative descriptive study conducted by the primary investigator and a lexical computerized analysis were explored using a parallel convergent mixed-methods design (Creswell, 2015).

Methods

A parallel convergent mixed-methods design calls for qualitative and quantitative data to be collected in parallel and analyzed separately, followed by the merger of the two sets of findings (Creswell, 2012; Creswell, 2015; Creswell & Plano Clark, 2011). This design was chosen for this study as our aim was to examine the convergence of the findings of a computerized lexical analysis (i.e., a quantitative approach) and a content analysis (i.e., a qualitative approach) both conducted on text data from illness narratives of people with schizophrenia. The illness narratives and the parent study from which they were drawn are described in Chapter 1. Below we describe the two analyses conducted on the narratives and the procedures used to examine the convergence of the two sets of findings.

Content Analysis of the Illness Narratives

The primary investigator had conducted a qualitative study to analyze participant responses to the IPII interviews (Lysaker et al., 2002). The study purpose was to describe common HRQoL concerns experienced by people with schizophrenia. Qualitative descriptive methods as described by Sandelowski (2000) and standard content analysis procedures (Miles, Huberman, & Saldaña, 2014) were used. The methodology and complete results of this study are presented elsewhere.

The findings of the qualitative study included four major categories of HRQoL concerns, each with a number of subcategories. The four major categories and their subcategories (in parentheses) were as follows: social relationships (romantic, family, friends, strangers), psychiatric symptoms (positive symptoms, negative symptoms, cognitive symptoms), psychiatric care (medications, hospitalization, relationships with health care providers), and employment (difficulty getting or maintaining employment, interpersonal conflicts in the workplace, benefits/satisfaction from work). Hereafter, the categories and/or subcategories that were identified in this study are referred to as HRQoL concerns. The HRQoL concerns are described in Table 4.1.

Computerized Lexical Analysis of the Illness Narratives

To conduct the computerized lexical analysis, the primary investigator selected the Linguistic Inquiry and Word Count (LIWC) software (Pennebaker, Booth & Francis, 2015a) because it provides nuanced word categories and has been previously used with people with schizophrenia (Buck & Penn, 2015b). Moreover, LIWC is widely used in social sciences to calculate the percentage of text data that falls within domains relevant to psychological processes, emotions, and social relationships (Buck, Minor & Lysaker, 2015a; Minor et al., 2015; Minor, Davis, Marggraf, Luther & Robbins, 2018). In its most current version (LIWC2015; Pennebaker et al., 2015a), the LIWC software examines words in a text file and matches each word to a dictionary of more than 6400 word stems, organized into 90 word categories (e.g., social, family, friends, positive emotions, negative emotions, perceptual, biological, work).

Before running the LIWC program (LIWC2015; Pennebaker et al., 2015a) on the participants' narratives, all interviewer prompts were removed from the transcripts to ensure that results would reflect only participants' words. For each participant's narrative, the LIWC (Pennebaker et al., 2015a) produced a percentage of word use (hereafter referred to as the LIWC score) for pre-selected categories. The resulting LIWC output was saved in a Microsoft Excel (2016) file. Descriptive statistics were calculated and displayed.

Integration of Content Analysis and Computerized Lexical Analysis

Several procedures were used to integrate the two analyses. The integration occurred in three stages.

Stage 1: Selecting which HRQoL concerns identified in the qualitative study could be paired with the LIWC word categories. The primary investigator examined the HRQoL concerns that had been identified in the qualitative study to determine which of these concerns had LIWC categories that appeared to be related. Through group discussion, the team determined that six HRQoL concerns had matching LIWC categories. Table 4.1 lists the HRQoL concerns (categories and subcategories) with descriptions of each juxtaposed with the corresponding LIWC categories along with examples of LIWC words that comprise the categories. The HRQoL concerns for which there are no corresponding LIWC categories are shaded in gray and were not included in the integration of the findings.

Stage 2: Quantifying the findings of the qualitative study. In order to integrate the findings of both analyses, the primary investigator quantified all qualitative data related to the six HRQoL concerns. The process of transforming qualitative data to numerical data has been called "quantitizing" (Tashakkori & Teddlie, 1998, p. 126) or "quantitative translation" (Boyatzis, 1998, p. 129). By converting narrative data into a numerical form that is compatible with the quantitative findings, the convergence of two sets of findings can be explored (Chang, Voils, Sandelowski, Hasselblad & Crandell, 2009).

Our purpose in quantifying the qualitative data was to provide a numerical rating of the degree to which the participants focused on each of the six HRQoL concerns that were paired with LIWC categories. To accomplish this, two team members independently color-coded all text units (e.g., words, phrases, sentences, stories) in the 20 transcripts that were related to one of the six HRQoL concerns. The primary investigator compared and merged the codes from team members. The few differences in how the text units were coded were resolved by discussion and consensus in team meetings.

Because the text units ranged from several words to lengthy stories relevant to one of the HRQoL concerns, a rating system was developed to capture the extent to which each text unit reflected the HRQoL concern. Each text unit was determined to be a remark, an elaboration, or a prolonged discussion. A remark is a relatively brief utterance (e.g., one or two shorts phrases, a short sentence) in which a participant reflects a concern but does not dwell on it. An elaboration is a longer utterance (e.g., several sentences) in which a participant expresses a concern and expands upon it by providing some explanation and detail. A prolonged discussion is a relatively lengthy monologue (e.g., many sentences) in which a participant expounds upon a concern by providing considerable and sometimes repetitious detail. Each text unit was independently rated as one of these three types of text units by two team members. The primary investigator compared the ratings and any differences were resolved by discussion and consensus. Based on the assumption that the three types of text units reflected the extent of the HRQoL concern experienced by the participant, each type was assigned a weight as follows: a remark=1 point, an elaboration = 3 points, and a prolonged discussion = 15 points. To calculate an index of the extent to which the participants expressed each concern, these weights were summed for each HRQoL concern in Table 4.2.

Stage 3: Integrating the findings from both analyses. In order to explore the extent to which the findings of the content analysis and the LIWC analysis converged, Pearson correlation coefficients were calculated to examine associations between the quantified HRQoL concerns and the LIWC scores. Because of our low sample size, we focused on the magnitude of the findings in addition to their statistical significance. Data analysis was conducted with SPSS software (version 25 2016). Consistent with Cohen’s (1992) criteria for correlation coefficients, effect sizes > .1 were considered small, > .3 were considered medium, and > .5 were considered large.

Table 4.1

HRQoL Concerns and their Matching LIWC Categories

HRQoL Concerns Identified in Qualitative Study (Categories)	**HRQoL Concerns Identified in the Qualitative Study (Subcategories)**	**Brief Description of Categories and Subcategories**	**Matching LIWC Categories and Hypothesized Relationship**	**Word Examples from LIWC Categories**
Social Relationships		Lack of relationships or relationships that were conflictual or deficient in some way. Relationships that provided companionship, passion, or support.	Social processes (+)	Mate, talk, they, you, story, society, said, hidden, he, his, told, talk, public, us, listen, crowd, call.
	Romantic relationships	Lack of romantic relationships due to mental illness. Romantic relationships that prevented loneliness and brought happiness.		
	Family relationships	Being abandoned, ignored, or merely tolerated by family members. Meaningful family relationships that provided guidance, love, and motivation to do well.	Family (+)	Daughter, dad, aunt, mother, married, wife, brothers, nieces, daughter, sons, father.
	Friendships	Lack of meaningful friendships. Meaningful friendships that contributed to a sense of social support.	Friends (+)	Buddy, neighbor, guys, fellow, dudes, friends, gang, comrades, squad.
	Strangers	Being treated by strangers in ways that were demeaning, threatening, or cruel.		
Psychiatric symptoms		Psychiatric symptoms that detracted from well-being and impaired everyday functioning.		
	Positive symptoms	Frightening or disturbing thoughts such as being watched, monitored, controlled by outside forces, or being surrounded by evil.	Perceptual processes (+)	Look, heard, feeling, say, look, music, loud, shining, eye, see, listen, quiet, spoken.

HRQoL Concerns Identified in Qualitative Study (Categories)	HRQoL Concerns Identified in the Qualitative Study (Subcategories)	Brief Description of Categories and Subcategories	Matching LIWC Categories and Hypothesized Relationship	Word Examples from LIWC Categories
	Negative symptoms	Feeling numb, lacking motivation or ambition, having little energy, and not experiencing pleasure.	Affective processes (+)	Happy, cried, emotions, good, bad, depression, didn’t like, I like, lost, excited, sad, energy, bored, love.
	Cognitive symptoms	Experiencing memory and attention deficits.		
Psychiatric care		Experiencing beneficial aspects of psychiatric care. Experiencing negative aspects of psychiatric care.		
	Medications	Experiencing medication side effects such as sterility, sedation, impaired speech, or personality changes. Experiencing the benefits of medication such as a decrease in hallucinations, relief from anxiety, or anger control.		
	Hospitalization	Experiencing negative aspects of hospitalizations because these facilities were believed to be for abnormal people. Experiencing beneficial aspects of hospitalizations which represented an opportunity to learn about their illness, develop coping skills, relax and socialize, obtain referrals for providers, benefit from group therapy, and access training opportunities.		
	Relationships with health care providers	Lacking quality relationships and services from health care providers. Experiencing meaningful relationships with health care providers who provided		

HRQoL Concerns Identified in Qualitative Study (Categories)	HRQoL Concerns Identified in the Qualitative Study (Subcategories)	Brief Description of Categories and Subcategories	Matching LIWC Categories and Hypothesized Relationship	Word Examples from LIWC Categories
		valuable information about treatments, taught skills to help control the symptoms, and provided guidance to set goals.		
Employment		Experiencing difficulties getting jobs, maintaining employment, or interacting with co-workers detracted from well-being. Feeling productive contributed to a sense of well-being.	Work (+)	Job, work, boss, completed, trade, learnt, industry, hire, successful, perform, produce.
	Difficulty getting or maintaining employment.	Losing jobs because of psychiatric symptoms or medication side effects.		
	Interpersonal conflicts in the workplace	Confronting coworkers for perceived maltreatment, becoming irritable, getting into physical altercations.		
	Benefits/satisfaction from work	Hoping to get a job in the future to become a productive person, be independent, and have a better life. Feeling proud and excited about current jobs.		

Results

Quantification of the HRQoL Concerns

The quantified HRQoL concerns scores are summarized in Table 4.3. The HRQoL concerns discussed most extensively by the participants were related to their social relationships. In regard to social relationships, concerns related to family relationships were discussed more extensively than concerns related to friend relationships. In regard to symptoms, positive symptoms were discussed more extensively than negative symptoms. Additionally, all HRQoL concerns scores had large standard deviations, indicating that there was wide variably related to how extensively the HRQoL concerns were discussed by the participants.

Table 4.3
Descriptive Statistics for HRQoL Concerns Scores

HRQoL concerns	HRQoL concerns scores		
	Mean score	Standard deviation	Ranges
Social relationships	55.3	52.01	7 - 200
Family relationships	27.3	32.04	0 - 133
Friends relationships	4.5	5.1	0 - 20
Symptoms			
Positive symptoms	14.85	28.11	0 - 128
Negative symptoms	4.35	4.52	0 - 18
Employment	16.1	18.7	3 - 88

LIWC Results

For each participant, the LIWC analysis indicated what percentage of speech fell into selected LIWC categories. Participants, on average, used a total of 5304 words (range of 670 to 18,413). Table 4.4 summarizes descriptive statistics regarding LIWC scores. The LIWC analysis revealed that the largest average percentage of participants' words fell in the social processes category, followed by the affective processes and work categories. Within the LIWC social processes category, a larger average percentage number of participants' word fell more in the family category than in the friend category. Additionally, all selected LIWC scores had large standard deviations, indicating that there was wide variably related to what percentage of speech fell into selected LIWC categories.

Table 4.4

Descriptive Statistics for Selected LIWC Categories

LIWC category	LIWC category scores		
	Mean score	Standard deviation	Ranges
Social processes	10.79	3.14	6.36 – 17.40
Family	0.95	0.85	0.31 – 3.58
Friends	0.27	0.18	0 – 0.65
Perceptual processes	1.96	1.25	0.88 – 6.63
Affective processes	3.67	0.94	1.94 – 5.14
Work	2.22	1.02	0.60 – 4.94

Convergence Between the Quantified HRQoL Scores and the LIWC Scores

Table 4.5 summarizes the hypothesized relationships and the Pearson correlation coefficients (r) between quantified HRQoL concerns scores and the matching LIWC category scores. For all pairs, correlation coefficients were positive and congruent with the direction of the hypothesized relationships. The magnitude of the correlation was reflected by a large effect size for the positive symptoms/LIWC perceptual processes pair (r = .913). This correlation was statistically significant (p = .000). The magnitudes of the correlations were reflected by medium effect sizes for the social relationships/LIWC social processes pair (r = .418), the friend relationships/LIWC friend pair (r = .308), and the family relationships/LIWC family processes pair (r = .462). This latter correlation was statistically significant (p = .04). Finally, the magnitudes of the correlations were reflected by small effect sizes for the employment concerns/ LICW work pair (r = .192) and the negative symptoms/LIWC affective processes pair (r = .294).

Table 4.5

Pearson Correlations between HRQoL Concerns Scores and LIWC Scores

HRQoL concerns	**LIWC category**	**Hypothesized relationship**	**Correlation using LIWC % score**	
			r	p
Social relationships	Social processes	+	.418	.067
Family relationships	Family	+	**.462***	.04
Friends relationships	Friend	+	.308	.187
Positive symptoms	Perceptual processes	+	**.913****	.000
Negative symptoms	Affective processes	+	.294	.209
Employment	Work	+	.192	.417

Note.
*. Correlation is significant at the 0.05 level (2-tailed).
**. Correlation is significant at the 0.01 level (2-tailed).

Discussion

Computerized lexical analysis showed both strengths and weaknesses in identifying HRQoL concerns described by people with schizophrenia. On one hand, the findings provide some preliminary evidence that computerized lexical analysis may be used to identify HRQoL concerns in this population. First, 6 of the 17 HRQoL concerns identified in our qualitative study (social relationships, family relationships, friend relationships, positive symptoms, negative symptoms, employment) had corresponding LIWC categories, suggesting that the LIWC has the potential to assess text data to reveal HRQoL concerns in some domains. Second, the correlations for the hypothesized relationships were all in the expected direction, with effect sizes ranging from small to large. Third, significant correlations were found between two of the pairs of quantified HRQoL scores and their corresponding LICW scores (family relationships/LIWC family and positive symptoms/LIWC perceptual processes). For these two pairs, the quantified HRQoL scores, based on our ratings of remarks, elaborations, and prolonged discussions, and the percentage of text data that fell within the corresponding LIWC categories were significantly associated. Together these findings suggest convergence of the two methods in identifying some of the HRQoL concerns described by participants.

On the other hand, many HRQoL concerns identified in the content analysis had no corresponding LIWC categories, suggesting that the LIWC would not be useful in assessing all HRQoL concerns that may be important to people with schizophrenia. For this study, we selected the LIWC because it is one of the most widely used computerized lexical analysis software and because of its previous use in schizophrenia research. However, the LIWC was developed to calculate the percentage of text data that falls within domains relevant to psychological processes, emotions, and social relationships (Buck et al., 2015a; Minor et al., 2018), but not HRQoL concerns specifically. To use computerized lexical analysis for this purpose, additional LIWC categories would be needed to account for a broader range of HRQoL concerns. Based on these findings, we conclude that while the LIWC may hold promise for assessing HRQoL concerns in this population, it currently lacks adequate lexical categories to measure a wide variety of HRQoL concerns.

Limitations

The findings of the current study must be considered in the context of the limitations from both the content analysis and the LIWC analysis. A limitation of both approaches was that the illness narratives that were analyzed were drawn from a larger study that was not aimed at exploring HRQoL. Additionally, although the procedures we used to quantify the qualitative findings offer a promising approach, these are still untested and may require further refinement. At the integration level, even though we found that the LIWC may hold promise for identifying HRQoL concerns, running the Pearson Correlations with larger samples would provide greater statistical power to identify relationships. Finally, the LIWC analysis accounts for the length of the interviews (Pennebaker et al., 2015a), whereas the procedures we used to quantify the qualitative data did not, possibly diminishing the correlations between the two sets of scores.

Implications for Research

Despite these limitations, the findings from the current study tentatively suggest that, with further development, computerized lexical analysis might be useful to identify HRQoL concerns in people with schizophrenia. The next step in this line of research would be to create and validate a new HRQoL lexical dictionary that would provide word categories that could match a wide variety of HRQoL concerns experienced by people with schizophrenia. For example, this could be done by developing a new HRQoL LIWC dictionary following procedures used to develop previous versions of the LIWC dictionary (Pennebaker, Boyd, Jordan & Blackburn, 2015b). These procedures occur in five steps. In Step 1, Word Collection, a list words for new categories are generated from several sources, including previous versions of the LIWC dictionary, current measurement scales, and group brainstorming. In Step 2, the Judge Rating Phase, each word in a category is examined by judges and rated in terms of "goodness of fit," resulting in a working version of the dictionary. In Step 3, Base Rate Analyses, texts from several sources including blog posts, spoken language studies, Twitter, and

Facebook are analyzed to determine how frequently category words are used in different contexts. In Step 4, Candidate Word List Generation, several sources of language are explored for high frequency words to expand the word categories. In Step 5, Psychometric Evaluation, all words from the developed categories are used to compute internal consistency statistics and determine internal and external validity.

If computerized lexical analysis is shown to be a valid and reliable way to assess HRQoL in people with schizophrenia, it could be used in research to further explore the phenomenon. For example, studies using computerized lexical analysis could be used to assess whether HRQoL concerns differ in different demographic subgroups of people with schizophrenia (e.g., gender, race/ethnicity) or in persons at different levels along the schizophrenia-spectrum (e.g., schizophreniform, schizoaffective). Studies could also investigate whether lexical scores were associated with other clinically relevant variables, such levels of functioning and symptomatology, to better understand the role of HRQoL in treatment outcomes. Once fully developed and validated, computerized lexical analysis may also provide an effective way to assess HRQoL in clinic settings and to support clinical decision-making by identifying directly and quickly which aspects of HRQoL are the most concerning to patients.

Conclusion

This exploratory study illustrates the potential of computerized lexical analysis to identify some HRQoL concerns that prior qualitative research indicated matters to people with schizophrenia. Further work is necessary to develop a computerized lexical analysis tool for the purpose of assessing HRQoL concerns in people with schizophrenia. Such a tool would have the potential to advance research on HRQoL in this population and eventually to provide a viable way to assess HRQoL concerns in the clinical setting.

Table 4.2

HRQoL Concerns Scores by Participant

HRQoL qualitative concerns by Participants	**Number of remarks (R)**	**Number of elaborations (E)**	**Number of prolonged discussions (PD)**	**HRQoL concerns scores weighted by R, E, and PD R=1, E=3, PD=15**
13005				
Social	21	25	0	96
Family	4	4	0	16
Romantic	6	13	0	45
Friends	3	2	0	9
Strangers	8	6	0	26
Symptoms				
Positive	26	29	1	128
Negative	7	1	0	10
Employment	4	5	0	19
13006				
Social	14	12	0	50
Family	4	2	0	10
Romantic	4	4	0	15
Friends	0	1	0	3
Strangers	6	5	0	21
Symptoms				
Positive	3	0	0	3
Negative	0	0	0	0
Employment	5	3	0	14
13007				
Social	14	7	0	119
Family	6	0	0	6
Romantic	0	3	0	9
Friends	6	1	0	9
Strangers	2	3	0	11
Symptoms				
Positive	5	0	0	5
Negative	2	2	0	8
Employment	8	1	0	11
13010				
Social	7	1	0	10
Family	1	1	0	4
Romantic	2	0	0	2
Friends	0	0	0	0
Strangers	4	0	0	4
Symptoms				
Positive	4	0	0	4
Negative	2	0	0	2
Employment	1	1	0	4

HRQoL qualitative concerns by Participants	**Number of remarks (R)**	**Number of elaborations (E)**	**Number of prolonged discussions (PD)**	**HRQoL concerns scores weighted by R, E, and PD R=1, E=3, PD=15**
13012				
Social	18	9	2	75
Family	12	6	2	70
Romantic	2	0	0	2
Friends	1	0	0	1
Strangers	3	3	0	12
Symptoms				
Positive	2	2		8
Negative	2	0	0	2
Employment	8	2	1	29
13015				
Social	9	8	0	33
Family	4	1	0	7
Romantic	2	3	0	11
Friends	2	1	0	5
Strangers	1	3	0	10
Symptoms				
Positive	1	3	0	10
Negative	0	0	0	0
Employment	5	5	1	35
13017				
Social	4	1	0	7
Family	0	0	0	0
Romantic	2	0	0	2
Friends	0	1	0	3
Strangers	2	0	0	2
Symptoms				
Positive	0	0	0	0
Negative	0	0	0	0
Employment	1	2	0	7
13028				
Social	18	2	0	24
Family	10	1	0	13
Romantic	5	1	0	8
Friends	3	0	0	3
Strangers	0	0		0
Symptoms				
Positive	3	2	0	9
Negative	2	0	0	2
Employment	2	2	0	8
13030				
Social	7	6	0	25
Family	3	5	0	18

HRQoL qualitative concerns by Participants	**Number of remarks (R)**	**Number of elaborations (E)**	**Number of prolonged discussions (PD)**	**HRQoL concerns scores weighted by R, E, and PD R=1, E=3, PD=15**
Romantic	1	1	0	4
Friends	1	0	0	1
Strangers	2	0	0	2
Symptoms				
Positive	0	0	0	0
Negative	2	0	0	2
Employment	6	3	0	15
13031				
Social	2	2	0	8
Family	0	0	0	0
Romantic	1	1	0	4
Friends	1	1	0	4
Strangers	0	0	0	0
Symptoms				
Positive	1	1	0	4
Negative	0	0	0	0
Employment	3	0	0	3
13032				
Social	17	13	0	56
Family	6	3	0	15
Romantic	6	5	0	21
Friends	0	1	0	3
Strangers	5	4	0	17
Symptoms				
Positive	2	8	0	26
Negative	6	4	0	18
Employment	2	1	0	5
13034				
Social	8	8	0	32
Family	1	5	0	16
Romantic	1	0	0	1
Friends	2	0	0	2
Strangers	4	3	0	13
Symptoms				
Positive	2	0	0	2
Negative	2	0	0	2
Employment	7	2	0	13
13035				
Social	14	6	0	32
Family	5	3	0	14
Romantic	5	3	0	14
Friends	0	0	0	0
Strangers	4	0	0	4
Symptoms				
Positive	9	4	0	21

HRQoL qualitative concerns by Participants	**Number of remarks (R)**	**Number of elaborations (E)**	**Number of prolonged discussions (PD)**	**HRQoL concerns scores weighted by R, E, and PD R=1, E=3, PD=15**
Negative	2	1	0	5
Employment	9	2	0	15
13036				
Social	11	6	0	29
Family	1	2	0	7
Romantic	4	3	0	13
Friends	3	0	0	3
Strangers	3	1	0	6
Symptoms				
Positive	10	8	0	34
Negative	5	1	0	8
Employment	5	1	0	8
13037				
Social	24	3	1	48
Family	5	0	1	20
Romantic	5	1	0	8
Friends	3	1	0	6
Strangers	11	1	0	14
Symptoms				
Positive	2	3	0	11
Negative	4	0	0	4
Employment	18	4	1	45
13038				
Social	59	27	4	200
Family	23	14	4	115
Romantic	11	4	0	23
Friends	11	3	0	20
Strangers	14	6	0	32
Symptoms				
Positive	3	3	0	12
Negative	7	0	0	7
Employment	22	7	3	88
23008				
Social	12	10	1	57
Family	10	6	1	43
Romantic	0	0	0	0
Friends	1	1	0	4
Strangers	1	3	0	10
Symptoms				
Positive	1	0	0	1
Negative	2	2	0	8
Employment	3	2	0	9
23018				

HRQoL qualitative concerns by Participants	**Number of remarks (R)**	**Number of elaborations (E)**	**Number of prolonged discussions (PD)**	**HRQoL concerns scores weighted by R, E, and PD R=1, E=3, PD=15**
Social	6	10	0	36
Family	5	10	0	35
Romantic	1	0	0	1
Friends	0	0	0	0
Strangers	0	0	0	0
Symptoms				
Positive	0	0	0	0
Negative	0	0	0	0
Employment	0	2	0	6
23020				
Social	31	18	5	160
Family	16	14	5	133
Romantic	5	1	0	8
Friends	8	2	0	14
Strangers	2	1	0	5
Symptoms				
Positive	4	2	0	10
Negative	1	1	0	4
Employment	7	1	0	10
23027				
Social	6	1	0	9
Family	4	0	0	4
Romantic	1	0	0	1
Friends	0	0	0	0
Strangers	1	1	0	4
Symptoms				
Positive	3	2	0	9
Negative	2	1	0	5
Employment	6	1	0	9

CHAPTER 5

Introduction

The overarching purpose of this dissertation was to conduct an in-depth exploration of HRQoL in people with schizophrenia. Chapter 2 describes an integrative review conducted to identify and describe factors associated with physical QoL in people with schizophrenia. Chapter 3 describes a qualitative descriptive study that builds upon the findings of the first study by identifying and describing HRQoL concerns of people with schizophrenia based on their illness narratives. Chapter 4 describes a mixed methods study that compares the findings of the qualitative descriptive study and the findings of a computerized lexical analysis of the same illness narratives to determine if computerized lexical analysis can be used to identify HRQoL concerns in people with schizophrenia. Chapter 5 synthesizes key findings from Chapters 2 through 4 and describes the ways in which the findings of the studies build on one another. In addition, this chapter explores the connections between the findings of these studies and the conceptual model of HRQoL as proposed by Ferrans, Zerwic, Wilbur and Larson (2005), identifies the strengths and limitations of the dissertation, provides recommendations for future research, and outlines implications for clinical practice.

Synthesis of Key Findings

The findings of each of the three papers can be synthesized into four overarching key findings. These key findings are as follows:

Key Finding 1: The Symptoms of Schizophrenia Play an Important Role in the HRQoL of People with Schizophrenia

The findings of all three studies suggest that the occurrence and severity of the symptoms of schizophrenia affect the HRQoL in persons who suffer from the illness. The integrative review revealed that the number and/or degree of severity of total symptoms and the level of general psychopathology were negatively associated with physical QoL. Confirming and extending this finding, the qualitative descriptive study revealed that positive, negative, and cognitive symptoms experienced by people with schizophrenia affected their sense of well-being and everyday functioning. Furthermore, the mixed-methods study suggested the people with schizophrenia are concerned with the perceptual and affective processes that are associated with positive and negative symptoms of schizophrenia. Together, these findings suggest that the symptoms schizophrenia play an important role in how people with schizophrenia experience the quality of their everyday lives.

Key Finding 2: The Quality of the Social Relationships of People with Schizophrenia is Associated with their HRQoL

Although the integrative review revealed that there is not enough evidence to conclude that social relationships are associated with physical QoL in people with schizophrenia, the qualitative descriptive study suggested that relationships with family, friends, romantic partners, and strangers play a role in their overall sense of well-being. The mixed methods study also revealed that people with schizophrenia were concerned about social relationships generally and relationships with family and friends more specifically. Taken together, therefore, the findings of the dissertation point to the importance of relationships in the lives of people with schizophrenia.

Key Finding 3: In People with Schizophrenia, HRQoL is a Complex and Multidimensional Experience

The findings of all three studies suggest that the HRQoL of people with schizophrenia is a multidimensional experience that involves physical, mental, emotional, and social aspects and is influenced by a number of factors. The focus of the integrative review was on physical QoL, which was shown to be associated not only with the symptoms of schizophrenia, but also with depression, obesity or body mass index, and physical activity. Similarly, the findings of the qualitative descriptive study revealed that the HRQoL concerns of people with schizophrenia were not limited to their symptoms and social relationships, but also included concerns about the psychiatric care they received and their employment experiences. These other dimensions or influencing factors were not reflected in the LIWC categories but would likely need to be considered if computerized lexical analysis was to be used to identify HRQoL concerns in this population.

Key Finding 4: The HRQoL of People with Schizophrenia Can be Assessed in a Number of Ways

The findings of the three studies demonstrate that the HRQoL of people with schizophrenia can be assessed in several ways. The integrative review revealed that many studies use standard instruments with well-established psychometric properties to measure QoL in this population. The two most frequently used were the World Health Organization Quality of Life Scale-Brief version (WHOQOL-BREF; WHOQOL Group,

1998) and the Short Form Health Survey (SF-36; Ware et al., 1993). The WHOQOL-BREF (WHOQOL Group, 1998) measures the domains of physical health, psychological health, social relationships, and environment. Similarly, the SF-36 (Ware et al., 1993) measures physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality, social functioning, role limitations due to emotional problems, and mental health and provides summary scores for physical health and mental health. The qualitative descriptive study demonstrated that HRQoL can be assessed by applying standard content analytic procedures to analyze illness narratives of people with schizophrenia in order to ascertain what concerns them most and to describe these concerns as situated in the context of their everyday lives. The mixed methods study revealed the computerized lexical analysis, with further development, shows promise of providing a quick and efficient strategy to identify some HRQoL concerns in this population. The dissertation findings thus demonstrate how each of these methods of assessing HRQoL might contribute to a deeper understanding of this phenomenon in this population.

Connection to Ferrans et al.’s (2005) HRQoL Conceptual Model

The findings of the dissertation resonate with many of the health outcomes and relationships outlined in the HRQoL conceptual model proposed by Ferrans et al. (2005). As described in Chapter 1, this conceptual model is centered on five health outcomes including biological function, symptoms, functional status, general health perceptions, and overall QoL. The model indicates that these outcomes are influenced by characteristics of the individual and characteristics of the environment. The characteristics of the individual purported to influence health outcomes include demographic, developmental, psychological, and biological factors. The characteristics of the environment purported to influence health outcomes are categorized as social or physical. Social influences include the influence of family, friends, and healthcare providers. Physical influences include the quality of home, neighborhood, and workplace.

This dissertation supported some of the relationships described in this conceptual model (Ferrans et al., 2005) with varying degree of evidence. Our studies provided limited evidence of the influence of characteristics of the individual on health outcomes. At the demographic level, while the integrative review provided mixed results, the qualitative descriptive study and the mixed methods study did not have a large enough sample with enough diversity to make conclusions about the influence of demographics. At the developmental level, although it would be important to understand better the influence of the developmental life stages on health outcomes, none of our studies addressed this. At the psychological level, our findings revealed that depression was associated with physical QoL. Additionally, some studies in the integrative review revealed that psychosocial factors such as coping skills, self-esteem, self-stigma, insight, or mindfulness were associated with physical QoL, but none of these psychosocial factors met our evidence criteria. At the biological level, factors such as metabolic syndrome, regional cerebral blood flow, total body fat, and genetics were also associated with physical QoL, but did not meet our evidence criteria.

Additionally, our studies supported the influence of characteristics of the environment on health outcomes described in the model. At the physical level, the integrative review revealed that the living arrangement for people with schizophrenia was associated with physical QoL, but again, these findings did not meet our evidence criteria. The qualitative descriptive study provided evidence that supports the influence of social factors on HRQoL as these results indicated that relationships with family, friends, and coworkers; interactions with strangers; and the quality of their relationships with health care providers, influenced their HRQoL. The importance of social relationships was also supported by the mixed methods study.

Strengths of the Dissertation

Each of the three studies will contribute to our understanding of HRQoL in people with schizophrenia. The integrative review was the first review to focus on physical QoL, an important domain to consider when planning integrative approaches to care. The qualitative descriptive study was one of the first of identify HRQoL concerns based on the perspectives of people with schizophrenia, and this information can be used plan comprehensive treatment strategies. The mixed methods study used an innovative approach to determine the potential of computerized lexical analysis to identify HRQoL in this population.

A strength of the dissertation is the use of a variety of methods to understand the phenomenon of HRQoL in people with schizophrenia. While the integrative review revealed specific factors that affected physical QoL in this population, the qualitative descriptive study expanded on these findings by providing a rich description of common HRQoL concerns based on the narratives of people with schizophrenia. Additionally, the mixed methods study provided early evidence of the potential of computerized lexical analysis to identify some HRQoL concerns described by people with schizophrenia based on the words they use in their illness narratives. Thus, the findings of each of the three studies build upon each other to contribute to an in-depth understanding of the phenomenon of HRQoL in people with schizophrenia using a different methodological lens.

Another strength of this dissertation is the use of illness narratives for two of the studies as this ensured the voices of people with schizophrenia were well represented in the findings. This allowed understanding of their concerns within the context of their day-to-day lives by exploring through their own words the complex ways in which their illness influences their well-being.

Limitations of the Dissertation

The findings of this dissertation should be understood in the context of several limitations. The illness narratives used for the qualitative descriptive study and the mixed methods study were obtained solely from the semi-structured Psychiatric Illness Interview (IPII) (Lysaker et al., 2002) conducted from the parent study. This was a limitation for the qualitative descriptive study because HRQoL could not be fully explored through open-ended follow-up or clarifying questions, and for the mixed methods study because the structure of the interview could have guided the participants to focus on certain topics, such as their symptoms, to the exclusion of other issues that may been of concern to them and would have been revealed in a more open-ended interview.

All three studies were limited due to the reliance on cross-sectional study designs. For the integrative review, the large majority of studies were cross-sectional and this prohibited conclusions about causality among the associated factors and physical QoL. For the qualitative descriptive analysis and the mixed methods study, the interviews were conducted at one point in time, and this did not allow exploration of how participants' perceptions of their functioning and well-being might have changed over time.

Because of the small sample size and the lack of diversity of the participants in the qualitative descriptive and mixed methods study, the HRQoL concerns of people with schizophrenia were described without exploring differences in demographic (e.g., gender, race/ethnicity) factors. While some of these factors were explored in articles in the integrative review, not enough evidence was found to draw conclusions about the influence of demographic factors on physical QoL. In addition, how HRQoL might differ among disorders along the schizophrenia-spectrum could not be explored in any of the studies.

Recommendations for Future Research

Several recommendations for future research can be made based on the findings of this dissertation. Although the findings indicate that HRQoL in people with schizophrenia include a number of dimensions and is influenced by several factors, the complex relationships among variables associated with HRQoL need to be further explicated. Future research should be guided by a conceptual framework that addresses the complexity of HRQoL and should explore the pathways that link the components of HRQoL with a variety of influencing factors. Future studies should include large diverse samples and be powered so that the influence of individual factors, such as gender, ethnicity, development stage, and diagnosis, and environmental factors, such as social support and treatment history, on HRQoL can be ascertained. Longitudinal studies that determine how HRQoL might evolve over the illness trajectory from when persons first become symptomatic to later in life are also needed. Finally, additional qualitative studies that use open-ended questions would be of use to explicate the full range of HRQoL concerns that matter most to people with schizophrenia. Further development of a computerized lexical analysis approach to assess HRQoL, using standard techniques, is recommended.

Implications for Clinical Practice

The findings of this dissertation have clinical implications for psychiatric mental health nurses and other mental health clinicians who work with people with schizophrenia. The results of all three studies support the implementation of best practices of symptom management as symptoms play a central role in how people with schizophrenia experience well-being. The findings also suggest that treatment strategies that address other influencing factors, such as depression and obesity, could also improve the HRQoL in this population. Clinicians should thus advocate for holistic delivery systems that provide treatments that enhance the overall well-being and functioning of people with schizophrenia.

In addition, the findings suggest that clinicians can assess HRQoL in a variety of ways. Standardized instruments that measure HRQoL, open-ended interviews focused on HRQoL concerns, and perhaps computerized lexical analysis, can provide clinicians with an in-depth understanding of the HRQoL of clients with schizophrenia.

Some of the findings of the three studies suggest possible topics that clinicians might address during therapeutic encounters with people with schizophrenia. For example, because social relationships with different groups of people seem to play an important role in the HRQoL of people with schizophrenia, clinicians might explore types of interactions clients desire with their family of origin, their desires regarding romantic relationships, or the effect of interactions with strangers on their sense of self. Similarly, clients might welcome the opportunity to discuss the quality of their relationships with health care providers and the meaning hospitalizations hold for them. Moreover, stressors associated with employment experiences or the influence of unemployment on clients' sense of self could provide important topics to discuss in sessions. While symptom reporting is often the focus of therapeutic sessions, the findings of the dissertation suggest that it might be important for clients to have the opportunity to discuss not only the existence or severity of symptoms but also the meaning these symptoms have for them. For example, our findings regarding the influence of cognitive symptoms on HRQoL suggest that memory disturbances not only interfere with day-to-day functioning but also create sadness due to the loss of parts one's life narratives.

Conclusion

In people with schizophrenia, HRQoL is a complex and multidimensional experience that is influenced by a number of factors. The occurrence and severity of psychiatric symptoms and the quality of the social relationships in particular play an important role in the HRQoL of people with schizophrenia. The findings of the current dissertation resonate with some of the relationships outlined in the HRQoL conceptual model proposed by Ferrans and colleagues (2005). The main strength of the dissertation is that the three studies use a variety of methods and the findings taken together provide an in-depth understanding of HRQoL in people with schizophrenia. The findings of this dissertation should be understood in the context of several limitations, including the reliance on cross-sectional study designs of all three studies as well as the small homogeneous sample and the use of illness narratives that had been obtained for another purpose for the qualitative descriptive and mixed methods studies. Future research that uses larger and more diverse samples and longitudinal designs are recommended to capture the complex and dynamic evolution of HRQoL over the course of the illness trajectory. The findings of this dissertation suggest that psychiatric mental health nurses and other mental health clinicians should advocate for holistic approaches to care based on a comprehensive understanding of the variety of factors that influence the overall well-being of people with schizophrenia.

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CURRICULUM VITAE

Carlos M. Janela

Education

- Doctor of Philosophy in Nursing Science, Indiana University, earned at IUPUI, Indianapolis, IN (2014-2019)
- Bachelor of Science in Nursing, Indiana University, earned at IUPUI, Indianapolis, IN (2010-2014)

Grants / Fellowships

- Predoctoral Fellow, Institutional Research Training Grant (T32): Training in Behavioral Nursing Research, Indiana University School of Nursing, Indianapolis, IN (2014-2017)
- Indiana University School of Nursing Award (2017-2018)
- Indiana University School of Nursing Research Incentive Fund Fellowship (2014-2018)

Research training

- Member of The Cognition, Language, and Affect in Serious Psychopathology Laboratory (CLASP) run by Dr. Kyle Minor within the IU Department of Psychology, IUPUI. The CLASP focuses on identifying clinical risk markers of psychosis and implementing interventions for individuals at risk for or diagnosed with Schizophrenia-spectrum disorders (2015-2017)
- Translational clinical research at IU Health. Research assistant in the clinical and translational research and evaluation projects being conducted within Indiana

University Health (IUH). Engaged in organizational decision-making groups relevant to IUH priorities (2014-2015)

Awards

- Premiere 10 (Top 10 Graduate Students on Campus for scholarship, community service, and university involvement), Indiana University Purdue University Indianapolis (April 2018)
- Premiere 50 (Top 50 Graduate Students on Campus), Indiana University-Purdue University Indianapolis (April 2018)
- Rising Star of Research and Scholarship initiative of Sigma Theta Tau International Honor Society of Nursing. Indiana University School of Nursing (November 2016)

Certifications and Licenses

- Registered Nurse, State of Indiana (2014- Present)

Professional membership

- Sigma Theta Tau International Nursing Honor Society (2016- Present)

Presentations

- Janela, C. M., Minor, K. S., & Draucker, C. B. (July 2017). Understanding health related quality of life (HRQoL) in people with schizophrenia: What literature review, qualitative analysis, and computerized lexical analysis can tell us. Poster session presented at the Sigma Theta Tau International Nursing Research Conference, Dublin, Ireland.

- Janela, C. M. (July 2016). Health-related quality of life in schizophrenia: a conceptual model. Poster session presented at the Sigma Theta Tau International Nursing Research Conference, Cape Town, South Africa.
- Janela, C. M., & Wilson, L. (February 2015). Effectiveness of medication independent double check: findings from the literature and recommendations. Presented at the IU Health Medication Safety Advisory Committee. Indianapolis.
- Janela, C. M., & Kerley D. (November 2014). A review of Literature of Nurse Fatigue: Findings and Recommendations. Presented at the IU Health Evidence Based Practice Steering Committee. Indianapolis.
- Janela, C. M. (September 2014). Situational Awareness Fall Brief: A Qualitative Content Analysis. Presented at the IU Health Fall summit, Indianapolis.

Publications

- Abplanalp, S. J., Buck, B., Gonzenbach, V., Janela, C., Lysaker, P. H., & Minor, K. S. (2017). Using lexical analysis to identify emotional distress in psychometric schizotypy. *Psychiatry Research*, 2017(255), 412–417. doi: 10.1016/j.psychres.2017.06.076

Volunteer Service

- Member of the Student Advisory Group. Reviewed and advised on topics regarding the PhD program and students' experiences at IU School of Nursing (2017-2018)
- Moderated 2 conference sessions related to mental health issues: Practice Outcomes for Mental Health Issues and Perinatal Mental Health Related Issues.

Sigma Theta Tau International Nursing Research Conference, Cape Town, South Africa (June 2016)

- Volunteered in the multi-disciplinary group-based problem solving within the Innovation Forum from The Center for Health Innovation and Implementation Science. Topic: How should quality and safety initiatives be communicated and implemented? (February 2015)