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Peer Support Services Reaching People with Schizophrenia

Considerations for Research and Practice

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For Andrew and Grace

Preface

Peer support, or non-clinical recovery support and services provided by people with lived experience of behavioral health conditions, is a rapidly growing field in behavioral health. With a rising need for behavioral health services and a shortage of workers, further expansion of the peer workforce is on the horizon. The nuances in the evidence base behind peer support, however, are complex. This book helps to clarify the varied intervention strategies and activities that make up peer support, its varied outcomes, and proposed intermediary links between intervention and outcome. While the material presented here is primarily focused on people diagnosed with schizophrenia or other serious mental illnesses, the lessons learned and implications for practice apply to a wider population of people with various behavioral health challenges.

This book is aimed at researchers and practitioners who are interested in deepening their knowledge of the complexities involved in peer support and peer-delivered services to inform research and service delivery. The book's focus on a particularly complex mental health issue, that of schizophrenia, is intended to illustrate that a holistic approach to care including peer support should be available to all mental health service users, including those diagnosed with the disorders that are most often considered severe. The book primarily uses the term schizophrenia in accordance with current diagnostic terminology; however, I acknowledge the heterogeneity in the term as well as criticisms of its reliability and validity.

Chapter 1 provides an overview of schizophrenia as a public health problem, and Chap. 2 outlines current approaches to treatment. Chapter 3 broadly summarizes some important theoretical bases of peer support and proposes a conceptual framework of the multiple inputs and outcomes of peer support at different levels of the socioecological model. A brief history of the modern recovery movement and the origins of peer support is detailed in Chap. 4. Chapter 5 reviews the evidence of peer support in mental health generally, and Chap. 6 presents the review methodology

used to investigate its uses among people with schizophrenia specifically. Chapters 7 and 8 present the main findings: categorization of the varied components comprising peer support interventions and key issues in the field, respectively. Finally, Chap. 9 summarizes the findings and presents implications for research and practice.

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Contents

Abbreviations

ACT	Assertive Community Treatment
BMI	Body Mass Index
CATIE	Clinical Antipsychotic Trials of Intervention Effectiveness
CBD	Cannabidiol
CHW	Community Health Worker
CIL	Center for Independent Living
FEP	First Episode Psychosis
FGA	First-Generation Antipsychotic
HVN	Hearing Voices Network
IPS	Individual Placement and Support
MET	Metabolic-Equivalent Expenditure
mHealth	Mobile Health
NAMI	National Alliance for the Mentally Ill
NHS	National Health Service
PAD	Psychiatric Advance Directive
PORT	Patient Outcomes Research Team
RAMESES	Realist and Meta-narrative Evidence Synthesis: Evolving Standards
RCT	Randomized Controlled Trial
SAMHSA	Substance Abuse and Mental Health Services Administration
SGA	Second-Generation Antipsychotic
SMI	Serious Mental Illness
THC	Δ-9-Tetrahydrocannabinol

Chapter 1
Schizophrenia as a Public Health Problem

Schizophrenia is conceptualized as a mental disorder characterized by psychotic symptoms such as disorganization of thought and behavior, auditory or visual hallucinations, and paranoid and other delusional ideas [1]. In addition to these positive symptoms, the disorder is also characterized by negative symptoms such as flat affect, poverty of thought or speech, and lack of interest, pleasure, or motivation [1]. It is also associated with broad cognitive impairment that affects both social and nonsocial cognition [2]. Impaired social cognition manifests in difficulties identifying emotions, connecting with other people, inferring other people's thoughts, and reacting emotionally to others [3]. People experiencing schizophrenia often have difficulty interpreting social cues that allow people to gauge another person's moods and intentions [3]. These social deficits in cognitive functioning are associated with decreased community functioning [4].

The category of schizophrenia-spectrum disorders outlined in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) includes the following diagnoses: schizophrenia, schizophreniform disorder, schizoaffective disorder, delusional disorder, brief psychotic disorder, and psychotic disorder-not otherwise specified [5]. This book primarily uses the term schizophrenia; however, I acknowledge the considerable heterogeneity in the term [6] and criticism of its limited reliability and validity [7]. As such, the information presented here is intended to translate to all mental disorders involving the experience of psychosis.

1.1 Complex Etiology of Schizophrenia

Although a variety of risk factors have been identified for schizophrenia and psychosis more generally, exact causes are far from understood [8]. Genetics have been implicated, with the strongest known predictor of risk identified as having a close biological relative who is affected [9]. Results from adoption and twin studies

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suggest that this familial clustering of psychosis is due largely to genetic factors [8]. It should be noted, however, that this interpretation of the evidence from twin and adoption studies is not without criticism [10]. Importantly, no single gene or genetic variant has been implicated as a necessary and sufficient causal factor for schizophrenia or psychosis [8]. Tremendous technological advances have enabled a proliferation of genomic research which has implicated over 100 independent genetic variants, both common variants and those that rarely occur [8]. Additionally, polygenic analyses across other conditions suggest that genetic loci contributing to schizophrenia risk are also implicated in other mental and physical illnesses [8]. A significant limitation of the current genetic research is that most studies have relied on ethnically homogenous samples of White people from European descent [8]. Thus, while genetics appear to play a role in the development of schizophrenia and other psychotic disorders, their role is complex, not fully understood, and certainly not a complete explanation.

A host of environmental factors are also significantly associated with schizophrenia and psychosis risk [8]. These risks exist across prenatal, perinatal, childhood, and adolescent developmental stages [8]. For example, inadequate nutrition [11], maternal anemia [12], exposure to heavy metals [13], and maternal stress [14] in the prenatal period are all associated with later development of schizophrenia. Obstetric complications [15], season of birth [16], and preterm birth [17] are perinatal risk factors for psychosis. Bullying [18] and maltreatment [19] in childhood are associated with development of psychosis, as are cannabis [20] and tobacco [21] use in adolescence. Minority status [22], income inequality [23], and low socioeconomic status [24] in any of these developmental stages are associated with a later development of psychosis [8]. Environmental risk appears to be cumulative [25] so that exposure to a greater number of environmental risk factors is associated with earlier age of onset [26, 27]. Additionally, there is likely significant gene-environment interplay implicated in the development of psychosis [8]. More research that thoroughly assesses both psychopathology and environment at multiple points during development will advance our knowledge of gene-environment causation [8].

Psychological risk factors for schizophrenia and psychosis are also important. Trauma plays an important role in the development of many mental disorders [28–30]; however, its role in the development of psychosis has historically been overlooked in favor of biomedical explanations [31, 32]. Nevertheless, the experience of childhood or developmental trauma has consistently been shown to be associated with later development of psychosis [33], and a dose-response relationship has been demonstrated, with those experiencing the most severe abuse being at the highest risk for developing psychosis [34]. Approximately 70% of individuals with early psychosis have a trauma history [35]. Developmental trauma has been shown to be associated with both positive [36, 37] and negative symptoms [37]. Furthermore, the experience of later re-traumatization is also associated with worsened symptoms of psychosis, and it is worth noting that most psychiatric patients suffer serious physical or sexual assaults in adulthood [38–40]. In addition, the very experiences of psychosis and psychiatric hospitalization can be traumatizing [41–43].

In sum, there are numerous and diverse factors that are associated with the development of schizophrenia and psychosis, and our understanding of causation is limited at best. However, the experience of psychosis is generally perceived to be caused mainly by biological and genetic factors, perhaps more so than any other mental illness phenomena [44]. While a biopsychosocial model of schizophrenia and psychosis is often emphasized, the reported ratio of biological to psychosocial etiology of psychosis studies is 16:1 [45], in effect reducing a complex, multilevel phenomenon to a simple, single-level issue [46, 47]. A more complete understanding of the etiology of psychosis necessitates further consideration of psychological and social factors.

1.2 Public Health Burden of Serious Mental Illness

Serious mental illnesses (SMI), including schizophrenia, pose a significant public health burden. The criteria for SMI diagnosis are having any diagnosable mental disorder, excluding developmental and substance use disorders, as well as experiencing serious functional impairment that is due to the illness and interferes with at least one major life activity [48]. Approximately 4–5% of US adults have an SMI [48], and proportions are similar in other countries [49]. SMI is commonly associated with diagnoses of schizophrenia-spectrum disorders, severe bipolar disorders, or severe major depressive disorders. However, any diagnosed mental illness that causes significant functional impairment and substantially limits major life activities can constitute an SMI.

The burden of mental illness is particularly concentrated among those diagnosed with SMI, making it a leading cause of disability [1]. In the United States, the associated per-person lifetime economic burden of SMI is estimated to be $1.85 million dollars, due to substantially worsened health outcomes, raised medical costs, and reduced economic outcomes across the lifespan [50]. People with SMI have a mortality rate 4.5 times greater [51] and an average life expectancy between 10 and 25 years shorter than that of the general population [52, 53]. People with SMI are more likely to die of unnatural and natural causes than people without mental illness [54]. Natural causes (e.g., cardiovascular disease) account for most of this excess mortality [51].

In addition to increased morbidity and mortality, people with SMI also disproportionately face economic and social problems. Compared to the general population, they have higher rates of unemployment [55–59], underemployment [56, 60], housing instability [61], and homelessness [62–64]. Strikingly, over a third of people with SMI earn less than $10,000 annually [55]. Over a lifetime, they earn half a million dollars less per person and spend 13 fewer years in full-time employment than those without SMI [50]. SMI is associated with a higher risk of incarceration [65, 66] and its estimated prevalence among jail and prison populations ranges from 15% to 30% [67–69]. Comorbid substance use disorders contribute to

the overrepresentation of people with SMI in the carceral system [70]. Demonstrating the staggering incidence of incarceration among this population, people with SMI are jailed more frequently than they are hospitalized [71].

1.3 Public Health Burden of Schizophrenia

Schizophrenia considered alone also presents a significant disease burden and has enormous economic and social costs [72–74]. It is estimated that approximately 21 million people are living with schizophrenia, a number which is expected to continue rising with population aging and growth [72]. Despite affecting just 1% of the population, it is the 15th leading cause of disability worldwide [75]. Across several high-income countries, annual national costs associated with schizophrenia are estimated to be between US$94 billion and US$102 billion, with indirect costs contributing over half of the total costs [73]. Beyond economic costs, the humanistic burden is also of great concern. Schizophrenia is associated with decreased quality of life, comorbid depression, treatment side effects, and tremendous caregiver burden [74].

Furthermore, individuals experiencing schizophrenia have poor social and health outcomes. These include reduced social connections, reduced rates of employment, and an impaired ability to live independently [76]. Due in large part to the effects of deinstitutionalization, the criminalization of poverty and substance use, and an inadequate social safety net, people with schizophrenia disproportionately experience homelessness [77–79] and incarceration [69, 80]. Globally, people diagnosed with schizophrenia die between 13 and 15 years earlier than those without the disorder (Hjorthøj, Stürup, McGrath, & Nordentoft, 2017). Their risk of death is estimated to be between two and three times greater than that of the general population [81]. This reduced life expectancy can be attributed to unnatural (e.g., suicide) and natural (e.g., cardiovascular disease) causes [81]. Approximately 60% of all deaths among people with schizophrenia are due to natural causes [82]. Health behaviors such as smoking [81, 83], sedentary behavior [84], and substance use [82, 85] contribute to the heavy burden of mortality among people with schizophrenia. Furthermore, side effects of antipsychotic medications are known to be obesogenic and causally related to metabolic syndrome [81].

1.4 Substance Use Among People with Schizophrenia

Roughly half of people diagnosed with schizophrenia also have a comorbid substance use disorder, a rate that has not changed over time [86, 87]. The most common substances used by people with schizophrenia are the same as in the general