

KNOWLEDGE, PERCEPTIONS, AND BEHAVIORS OF PATIENTS
WITH SERIOUS MENTAL ILLNESS ON MENTAL HEALTH LITERACY

by

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ABSTRACT

KNOWLEDGE, PERCEPTIONS, AND BEHAVIORS OF PATIENTS WITH SERIOUS MENTAL ILLNESS ON MENTAL HEALTH LITERACY

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Nurses are frontline healthcare providers and perfectly positioned to improve the health literacy of patients and families in community, hospital, and all other healthcare settings. The aim of this study was to provide an understanding of the specific needs of individuals with serious mental illness (SMI) to help improve their mental health literacy (MHL). Understanding the knowledge, perceptions, and behaviors of individuals with SMI about mental health literacy may improve strategies and initiatives for MHL. The American Academy of Nursing (AAN) issued a policy brief on health literacy, stating the importance of assessing the patients' level of health literacy and ensuring that patients know how to self-manage their health. Nurses must ensure that patients have the information, tools, and resources needed to make informed decisions.

Qualitative descriptive research methodology was considered most appropriate for this study because the concept of MHL is complex and not easily measured. The Mental Health Literacy Model (MHLM) was the conceptual framework used for the study, and the semi-structured interview questions were derived from the MHLM. Fifteen participants were interviewed utilizing a semi-structured interview guide, and discussion was framed within the context of the MHL model. The study participants were recruited from a psychiatric outpatient clinic in the Metro New York area. The data were analyzed through thematic analysis to identify themes and subthemes. Themes were then analyzed in aggregate to identify overarching themes.

Additionally, a Computer-Assisted Qualitative Data Analysis Software (CAQDAS) called NVivo was used to analyze data.

The findings showed that participants' understanding of their mental illness, therapeutic alliance with their mental health provider, and having a patient advocate (mostly their family member) directly impacted their help-seeking behavior. Moreover, it influenced their decisions and adherence to psychopharmacologic treatment and psychotherapy. Consistent with the findings in the literature, the participants reported that stigma made them feel isolated and marginalized which delayed their help-seeking behavior, resulting in negative patient outcomes.

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DEDICATION

I dedicate my dissertation work to my parents, Isabel Salazar Resuma and Ildefonso Resuma, who passed away before I began my Ph.D. journey. Thank you for instilling in me the importance of education and being the best role models a daughter could ever have. You are the embodiment of humility and grace. Thank you for believing in me and for all the sacrifices you made, so I can continually improve myself.

PREVIEW

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Speak your truth quietly and clearly; and listen to others.

Even the dull and ignorant, they too have their story.

Max Ehrmann

I am so grateful for the love, support, and sacrifices of my family so I could complete my doctoral degree. To my husband, Scott, and my daughter, Isabelle, your relentless support and belief in me propelled me to keep going, even during those times when I was ready to give up. You have been an integral part of this challenging but most rewarding journey. To my daughter, Isabelle, I hope that I have shown you that with hard work, perseverance, passion, and the support of your family, you can achieve whatever you dream.

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Thank you to Dr. Sharon Wexler for sponsoring me so I can finally conduct my study. To Dr. D. Chen and Simone, thank you for your generosity in welcoming me to your outpatient clinic, and providing me and my participants a safe and conducive space to conduct my interviews. To my 15 brave participants, thank you for your trust in me in sharing your stories about your personal journeys in managing your mental illness and your desire to be included as productive members of the society. I hope together we can end the silence.

I. C.

PREVIEW

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PREVIEW

Chapter 1

OVERVIEW OF THE STUDY

Introduction

Patient Jose is a 45-year-old Hispanic male who has a dual diagnosis of bipolar disorder and substance abuse. He also has hypertension and diabetes. Jose has been in and out of the hospital for substance abuse rehabilitation over the last 10 years. He does not regularly go to his outpatient clinic as scheduled but rather to the emergency room when his symptoms worsen or when he runs out of his medications. Jose's support system is poor because most of his family live in the Dominican Republic, and he has been estranged from them. Furthermore, he has not made any meaningful relationships since he moved to the United States 10 years ago. Despite not graduating from high school, having fifth grade reading ability, and speaking limited English, Jose works at the local restaurant as a cook.

Today, Jose is standing by the nurses' station at the hospital waiting to be discharged. He is anxious to leave and tells his nurse, "I've been through this many times before. I know what to do. Just give me my prescriptions and I am out of here." His nurse explains that she has to give both verbal and written instructions when patients are discharged. She proceeds to tell him, "You have five medications, which include valproic acid to help stabilize your mood, olanzapine for your paranoid thoughts, metformin for your diabetes, hydrochlorothiazide for your blood pressure, and lorazepam only when needed for your anxiety." The nurse provides Jose with medication instructions and his appointment reminder for his psychiatrist. Jose flipped through the pages of discharge instructions, ensuring he has a prescription for his anxiety medications. Then he rushes out the door to the lobby where his girlfriend is impatiently waiting for him.

Unfortunately, the above scenario happens almost every day in healthcare settings with patients who have serious mental illness (SMI). For the purpose of this study, the definition of patients with SMI is patients who have one or more diagnoses of mental disorders combined with significant impairment in functioning (Substance Abuse and Mental Health Services Administration [SAMHSA], 2020). Often, patients with SMI need time and prompting to ask questions related to their health issues and discharge plans. In many cases, these patients do not even know what questions to ask or how to ask appropriate questions. The quality and method of discharge teaching are associated with hospital readmissions (Coleman et al., 2013; Payne, 2018; Peter et al., 2015).

Teach Back is a “procedure during which the patients describe information they have been taught, using their own words, to confirm understanding of the information” (Anderson et al., 2020, p. 95). It is one of several evidence-based methods in patient education and discharge instruction strategies (Chandar et al., 2019; Hong et al., 2019). However, nurses are not always able to perform Teach Back because of their large caseloads and increased patient acuity. Nurses do not have enough quality time with patients to provide them with opportunity to ask questions during the discharge process. Conversely, patients with SMI often take a passive approach to their healthcare because of myriad factors, one primary factor being health literacy (Berkman et al., 2011; Clausen et al., 2016). The Institute of Medicine (IOM et al., 2004) defined health literacy as the degree to which individuals have the capacity to obtain, process, and understand the basic health information needed to make appropriate health decisions.

In the case of patient Jose, it would be crucial to assess his health literacy and tailor an individualized health education approach that will improve his understanding and comprehension of how to manage his complex health condition. Additionally, an individualized approach

increases patients' engagement and ownership of their recovery process, which improves medication and treatment adherence (Joplin et al., 2015). Therefore, improving health literacy is an important factor in improving the adherence of patients with SMIs to their treatment and medication and preventing hospitalizations and readmission (Al Hathloul et al., 2016; Coleman et al., 2013). More importantly, the patient's level of health literacy is associated with increased mortality, rehospitalization, and the patient's ability to self-manage chronic illness, including SMI (Berkman et al., 2010; Handley et al., 2018; Mitchell et al., 2012; Moser et al., 2015; McNaughton et al., 2015). It is critical to understand the background of health literacy because mental health literacy is an outgrowth of health literacy. The term *health literacy* (HL) implies much more than reading, writing, and arithmetic skills. The World Health Organization (WHO) defined HL as "the cognitive and social skills which determine the motivation and ability of individuals to gain access to understand and use information in ways which promote and maintain good health" (Andrade et al., 2014). As a result, understanding HL is critical for understanding MHL.

Understanding Health Literacy

The process of achieving adequate HL starts with the individual knowing and understanding his or her current health context, in terms of diagnosis, treatment options, and plan of care (Lubman et al., 2017). The earlier definitions of HL focused the responsibility solely on the individual. However, in the past decade, the focus and definition of HL have evolved and are more comprehensive. HL is not only an individual characteristic but rather a constant interaction and collaboration between the skills of individuals, the providers, and the demands of the health system (Loan et al., 2018; Parnell, 2014). Patients with adequate HL are able to choose and implement appropriate treatment options, which ultimately can improve their current health

status to maintain and improve health (Berkman et al., 2011; Miranda et al., 2020; Parnell, 2014). The IOM et al. (2004) claimed that health literacy may affect the health of Americans and the ability of the healthcare system to provide effective and high-quality health care. People who struggle with health literacy tend to forego preventive health care, such as cancer screenings, and use expensive health services such as the emergency department more frequently because they find it challenging to understand health information and navigate our complex health system (Balakrishnan et al., 2017; Currier et al., 2001; Schumacher et al., 2013). Furthermore, Berkman et al. (2011) highlighted the complexities of the health system and the difficulties of navigating it; thus, they recommended that patients, providers, and healthcare systems work collaboratively to improve their communication skills and develop strategies to create a culture that promotes health literacy (Loan et al., 2018; Parnell, 2014). Adequate HL can positively influence patient engagement, which in turn makes patients more involved in the planning, decision making, and implementation of their treatment options.

When patients are engaged in their treatment, they are more likely to adhere to their treatment, which ultimately equates to better patient outcomes (Debussche et al., 2018; Jaffee et al., 2017; MacLeod et al., 2017; Wallace et al., 2016). In the case of individuals with mental illness, understanding their own treatment improves medication adherence and results in improved patient outcomes (Andrade et al., 2014; Clausen et al., 2016). In its landmark report *Health Literacy: A Prescription to End Confusion*, the IOM reported that 90 million adults in the United States have limited HL. This affects their ability to benefit fully from health care services. The IOM report highlighted that “improving individual health literacy requires great effort from the public health and health care systems, the education system, and society overall.” Knowing the background of HL, it is possible to move onto the literature supporting mental health literacy.

Understanding Mental Health Literacy

Mental health literacy (MHL) arose from the work on HL and is promoted by the WHO as an empowerment tool that aids people's participation in their health care (Kickbusch et al., 2013). Jorm et al. (1997) defined MHL as "knowledge and beliefs about mental disorders which aid their recognition, management or prevention" (p. 182). In order for individuals to gain MHL, they must first possess a certain level of HL to be able to read, comprehend, and apply health-related information (Kutcher et al., 2016; Lee et al., 2017; Lee et al., 2020a, 2020b; Lincoln et al., 2008; Lincoln et al., 2015a; Mantell et al., 2020; Poon et al., 2019). MHL is a significant determinant of mental health and has the potential to improve both individual and population health. MHL addresses an individual's knowledge of mental illness, attitudes, and help-seeking behaviors, including four domains: understanding how to obtain and maintain good mental health; understanding mental disorders and their treatments; decreasing stigma against mental illness; and enhancing help-seeking efficacy (Kutcher et al., 2016; Wei et al., 2013, 2015). Using a cross-sectional study design, Lee et al. (2020) examined associated factors of MHL to measure MHL; they focused on measuring the knowledge of different mental health aspects such as help seeking, knowledge of mental health resources, and willingness to receive services. The associated factors included health literacy, social support, and education level. The results showed that high MHL is linked to high literacy. Conversely, individuals with low health literacy are likely to have low MHL, difficulty in identifying psychiatric diagnosis correctly, and delayed help seeking (Lee et al., 2020). Additionally, individuals with serious mental illness have more difficulty understanding, appraising, and applying health-related information (Clausen et al., 2016; Galletly et al., 2012; Lincoln et al., 2015b; Mantell et al., 2020; Thorsteinsson et al., 2018).

Using the European Health Literacy Survey questionnaire (HLS-EU-Q), Mantell et al. (2020) examined the HL of individuals with mental illness compared with the general population. They found that individuals who were recently diagnosed with mental illness did not necessarily have much difficulty with literacy skills of understanding verbal and written health information, but they did have difficulty with putting health-relevant information into action. By contrast, the general population found it relatively easy to apply health-relevant information (Mantell et al., 2020). Evidence has demonstrated that the early identification of mental disorders increases help-seeking behaviors, and improved health outcomes can be achieved when an individual's MHL is improved (Cannon, 2019; Gorczynski et al., 2017).

Significance of the Study

Mental illness is common and debilitating. According to the National Institute of Mental Health (NIMH, 2019), 51.5 million Americans or one in five U.S. adults live with a mental illness. There are many different types of mental illness with varying degrees of severity. This study focused on patients with severe mental illness (SMI). It is imperative to improve the MHL of patients with SMI because non-adherence to treatment and medication, as well as relapse and re-hospitalizations, are high among people with SMI, even when they adhere to their medications and treatment (Yu et al., 2015). Additionally, the side effects of most psychotropic medications can be serious and sometimes irreversible. According to Piper et al. (2018), when patients possess an adequate degree of MHL and are engaged in their treatment, the possible adverse effects of medications may be prevented. Adequate MHL helps individuals with SMI improve early symptom identification, seek timely treatment, and manage their overall well-being (Clausen et al., 2016). Low health literacy and MHL impact patient outcomes and negatively

affect the economics of health care delivery (Sorenson et al., 2012). It is challenging for individuals with limited MHL to understand health information and navigate the healthcare system; they tend to forego preventive health care, such as cancer screenings, and instead use expensive health services such as the emergency department (Balakrishnan et al., 2017; Loan et al., 2018; Schumacher et al., 2013). In a study conducted by Mateo-Miller et al. (2016), patients diagnosed with depression missed their scheduled medical appointments 30% more often than patients without depression. Missed appointments contribute to the millions of dollars spent annually for health care (Sims et al., 2012). Nurses have a crucial role in improving the MHL of patients with SMI and, consequently, help improve their health outcomes.

Relevance to Nursing

Nurses are frontline health care providers and are perfectly positioned to improve the health literacy of patients and families in community, hospital, and other healthcare settings. In most cases, nurses have been designated to provide discharge planning and patient teaching of patients with SMI. However, there is no published literature on the source and nature of the information that these patients use for their perceptions and behaviors related to MHL. The results of this study provide an understanding for nurses about the source of understanding of individuals with SMI to help improve their HL as it relates to their MHL. Most recently, the American Academy of Nursing (AAN) issued a policy brief on HL that stated, “Health literacy acknowledges the need for assessing and addressing health literacy for every patient, every time, and in every health-care encounter; and ensuring patients know what they must do after all health care encounters to self-manage their health” (Loan et al., 2018, p. 97). Nurses must ensure that patients have the information, tools, and resources needed to make informed decisions.

Purpose of the Study

The purpose of this study was to understand the knowledge, perceptions, and behaviors of individuals with SMI about MHL. Understanding the knowledge, perceptions, and behaviors of individuals with SMI about MHL may improve strategies and initiatives on mental health literacy. Themes gathered from this study will offer information to other health professions information to design innovative programs that are individualized and to develop nursing and health policies to improve the MHL of individuals with SMI.

Summary

This chapter provided an introduction to understanding the concept of health literacy and mental health literacy, a brief background on the literature associated with HL and MHL, a description of the significance of the study as well as its relevance to nursing, and the purpose of the study.

Chapter 2 presents a robust review of the literature related and relevant to mental illness and its treatment, as well as health literacy, mental health literacy, and factors that influence mental health literacy.

Chapter 2

REVIEW OF LITERATURE

Introduction

The historical background of mental illness and the treatment of mental illness, as well as of health literacy and mental health literacy (MHL), were significant to this study because they provided a context for the perception of mental illness and how the MHL of individuals with serious mental illness (SMI) was often neglected. Additionally, the evolution of the different types of treatment of mental illness was brought into perspective. The history further addressed the issue of the lack of MHL that continues to exist and how SMI is a life-changing event for anyone diagnosed with the condition. Knowledge of the disease's past history and present reality may add more weight to understanding the impact they have on the lives of those involved. This may enable mental health providers to provide a more patient-centered care approach to increase the MHL of individuals with SMI to improve their help-seeking behaviors. Lastly, a review of literature on the factors that influence the MHL of individuals with SMI is discussed and highlights the importance of MHL in improving health outcomes for individuals with SMI.

Historical Background

Mental Illness and the Treatment of Mental Illness

The perception and interpretation of mental illness have evolved as our knowledge has changed and developed, especially within the contexts of different sociocultural environments. It is evident that MHL has not been a priority in recent history. Mental illness was mostly a label, and individuals with mental illness were not educated about their own illness and its treatment. Theories about the causes of mental illness have gone through a sequence of explanations related to the supernatural, natural, psychological, biological, and psychobiological (biopsychosocial).

Moreover, the treatment of mental illness depended on the theory based on the cause of the illness. As the etiology of mental illness evolved, so did the treatment of mental illness. However, individuals with mental illness were not educated about advances in diagnostic tests and treatment of mental illness and were only expected to be recipients of the treatment. To dispense with myths and misconceptions about mental illness and its treatment, it is crucial to improve the MHL of individuals with mental illness and educate them about how to diagnose mental illness properly and seek professional help (Angermeyer & Matschinger, 2003; Barney et al., 2009; Batterham et al., 2018; Cheng et al., 2018).

From 900 to 600 B.C., mental illness was believed to be caused by supernatural forces and considered the work of the devil. Persons who were believed to be “possessed” by the devil were not educated about the cause and were only expected to accept the treatment, which was mostly provided by village elders and religious leaders. Other common causes of mental illness during this early period were believed to be poor diet; disrespect towards the gods, teachers, and other authority figures; mental shock due to excessive fear or joy; and improper bodily activity. Additionally, mental illness was also viewed as a sequela of poor diet, poor sleep, air pollution, and poor attention to the cleanliness of the skin (Shorter, 1997). Herbs, ointments, acupuncture, charms, prayers, fasting, and exorcism were used to treat individuals with mental illness. In the meantime, purges, bloodletting, and emetics (or induced vomiting) were used for cases when the cause was believed to be other than a psychological or moral issue.

By the end of the 17th century, mental illness was mostly seen as an organic biological phenomenon, as in the case of the so-called “village idiots,” who most likely had mental retardation or schizophrenia from birth trauma (Shorter, 1997). This was the first time that early psychiatrists in Europe considered the possibility that mental illness can be hereditary or, as they

called it, “in their blood” (Shorter, 1997). Harsh physical treatment prompted the beginning of more humane, psychological, and personalized approaches. Thus began a period in which patients were given an opportunity to express themselves and describe their experiences in their own words—this was the beginning of psychotherapy. In 1890, Sigmund Freud introduced psychoanalysis, which recognized the relationship between physical issues such as hysteria and an understanding of the individual’s psychological processes.

The 19th century was considered the “great confinement” or the “asylum era.” However, by the late century, the term “asylum” had lost its original meaning as a place of refuge or safety and was associated with abuses (Shorter, 1997). Most patients within these asylums faced brutal treatment, and they did not even understand why they did because they were not consulted about their treatment. In the book *A History of Psychiatry: From the Era of the Asylum to the Age of Prozac*, written by Shorter in 1997, insulin coma therapy, Metrazol, lobotomy, and electroconvulsive therapy (ECT) were described as popular treatments during the great confinement, but all were considered controversial, specifically because of their adverse side effects.

In the early 1900s, researchers started to look systematically at the relationship between the mind and the brain through experiments related to psychopharmacology. Chlorpromazine was the first antipsychotic medicine administered to psychiatric patients in asylums and brought profound changes to the treatment of mental illness (Shorter, 1997). Psychotropic drugs were considered critical adjuncts to psychotherapy. These drugs helped patients participate in psychotherapy and engage in the social world (Braslow & Marder, 2019). They also enabled patients to be treated in their homes and the community without needing to be confined in a psychiatric hospital. The most significant era in the understanding of mental illness and its treatment occurred during the 1990s, which was proclaimed the decade of the brain (Ackerman,

1992). Advances in brain-imaging devices and the decoding of the human genome resulted in radical changes; mental health and mental illness were now understood as brain diseases (Laws, 2000). The shift from behavioral science to neuroscience led to discoveries of various psychotropic drugs such as Prozac, which was the first selective serotonin reuptake inhibitor (Shorter, 1997). Prozac was considered a medical breakthrough drug because it is known to be effective in treating depression, panic attacks, and a range of other psychiatric conditions with significantly few side effects (Smeraldi, 1998). Shortly after the discovery of Prozac, other psychotropic medications were developed, such as other selective serotonin reuptake inhibitors, serotonin norepinephrine reuptake inhibitors, and second-generation antipsychotic medications. All these advancements in psychopharmacology helped patients with SMI function independently in the community and have more autonomy in selecting various treatment options. Therefore, it is crucial to improve the health literacy and MHL of individuals with SMI so they can understand health information about their illness and treatment and seek early treatment (Kelly et al., 2007; Lindow et al., 2020; Olsson & Kennedy, 2010; Wei et al., 2013). Studies have shown that improved HL and MHL help individuals with SMI make informed decisions about their treatment as well as psychotropic medications that have adverse side effects which can affect their general health and well-being (Cannon, 2019; Cheng et al., 2018; Lubman et al., 2017).

Health Literacy

The historical background of health literacy (HL) provides an understanding of the evolution of MHL. In 1974, the term HL was used for the first time to describe its impact to the educational system, the healthcare system, and mass communication (Parnell et al., 2019). In 1998, the World Health Organization (WHO) defined HL as “cognitive and social skills which