Life and Lived Experiences of Adults With Chronic Mental Illness

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Author Note

I have no conflicts of interest to disclose.

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Date of Dissertation Defense: July 22, 2021

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Acknowledgments

I would first and foremost like to thank my committee for their time and effort they have put into my research. I would like to personally acknowledge Dr. Leihua Edstrom for her unconditional support and guidance throughout this research project. My professional relationship with Dr. Edstrom began when I first interviewed with her at Northwest University for a chance to be in the PsyD program. When I received my letter of acceptance from the university, I spoke with Dr. Edstrom about my academic plans and goals for my developing career as a psychologist. She and I have spent countless amounts of hours speaking with each other and learning from one another. Without her advocacy, I would not have been as successful as I am now with the conclusion of my academic career.

Next, I would like to give a unique acknowledgement to my wife without whom I would not have arrived at this point in my academics. She has been a foundation of hope, strength, and courage in times when all faith was depleting. She has inspired me to continue to push forward even in times of complete uncertainty and hopelessness. I recall on my first day of orientation in the summer of 2017 when my wife told me we were entering this path together, and together we will finish it. I owe this accomplish to her for all of the love, kindness, and selflessness she has given our marriage over the last 5 years.

Finally, I would like to give a special acknowledge to my parents who have supported my education since I began my undergraduate degree in 2013. They were always willing to pay every cent of tuition, books, supplies, and to live in dorms while I have been accomplishing my dream of becoming a psychologist. Lastly, I owe everything to God for His unconditional love, support, grace, and kindness throughout this process.

He has shown me my calling these past 5 years and how I will use this knowledge to help others heal and succeed.

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Abstract

Chronic mental illnesses such as schizophrenia or bipolar disorders can have lasting impacts and challenges for those who live with them. These challenges consist of routine difficulty, structured support, and how this population seeks out treatment (Conway et al., 2019). The rationale of this study was to understand how adults with chronic mental illness perceive treatment based on their lived experiences and what changes can be made to the field of behavioral health. This study used a phenomenological methodology to provide greater understanding and meaning of participants' treatment experiences.

This study recruited seven participants from an outpatient psychiatric organization to participate in an interview. Interview questions were constructed to understand how this vulnerable population relates to their mental health treatment, what their experiences have been with treatment, and what changes can be made to the field of behavioral health based on their lived experiences. Interview transcripts were coded using the ATLAS.ti software program to support the organization of the coding schemas. These schemas were then used to express themes and subthemes that addressed the research questions. Interrater reliability was established by computing a Cohen's weighted kappa on a portion of the transcripts to assess consistency of coding. Themes were identified from participants who described a variety of experiences that comprised of effective and ineffective methods of care.

Specific areas of effective care consisted of validation of participants' lived experiences and collaboration between providers for care. Ineffective care methods were being dehumanized/stigmatized based on diagnosis and a lack of education around

diagnoses. Study limitations were a lack of diversity in diagnoses and a smaller number of participants in the study. This study yielded research implications such as understanding treatment perceptions of inpatient psychiatric care compared to outpatient care. Specific policies such as educating practitioners to use person-centered language around a diagnosis may create a more welcoming environment for treatment. For instance, rather than stating schizophrenic, identify the person by their name or this person who has or lives with schizophrenia (American Psychological Association, 2020). These adaptations may assist in treating adults with chronic mental illness and reinforce higher levels of confidence to seek mental health treatment. In addition, these changes may strengthen familial and community supports for adults with chronic mental illnesses.

Chapter 1: Literature Review

Life and Lived Experiences of Adults With Chronic Mental Illness

Psychotic disorders are a cluster of different mental illnesses in psychiatric and psychological practices. According to the *Diagnostic and Statistical Manual for Mental Disorders,* 5th Edition (DSM-5), primary symptoms of psychosis are hallucinations, delusions, and/or paranoia (American Psychiatric Association [APA], 2013). Although an individual may present with all three symptoms, at least one symptom must be present to be diagnosed with psychosis. Psychosis can be seen in several diagnoses including brief psychotic disorder, substance or medication-induced psychosis, psychotic disorder due to another medical condition, or unspecified psychosis. Psychosis or psychotic symptoms are also seen in chronic psychotic disorders such as schizophrenia, schizoaffective disorder, schizophrenia spectrum disorder, and schizophreniform disorder (APA, 2013). Although each of these disorders have different presentations, treatments, and prognoses, individuals who live with psychotic disorders have varying life experiences.

Prevalence Rates of Mental Illnesses

Although mass media outlets or Hollywood productions present chronic mental illnesses (i.e., psychotic disorders) as a common aspect of our societies, mental illnesses are significantly less common. According to the DSM-5, chronic disorders such as schizophrenia has a prevalence rate of 0.3% to 0.7% in the United States and are commonly diagnosed among males. Schizoaffective disorders have a prevalence of 0.3% in the United States and is commonly diagnosed in females (APA, 2013). Although, disorders like schizophrenia and schizoaffective disorder present with psychosis as the primary symptoms, these disorders are also categorized with several other symptoms not related to psychosis (i.e., negative symptoms of schizophrenia and mood dysregulation in schizoaffective disorder). In schizophrenia, psychotic symptoms are classified as positive symptoms. Contrary to these symptoms sounding favorable, they are labeled “positive” because they are easier to treat with psychiatric medication. Negative symptoms of schizophrenia include anhedonia (i.e., lack of pleasure in everyday things), alogia (i.e., speech difficulties), lethargy, thought disorders, and isolation (APA, 2013). Negative symptoms are labeled as such due to the difficulty of treating them and they cannot be effectively treated with medications like positive symptoms can be (Belanger et al., 2018). Negative symptoms are primarily addressed with evidence-based psychotherapeutic interventions (i.e., talk therapy) to overcome feelings of lethargy, feelings of isolation, or anhedonia.

Schizoaffective disorders meet the DSM-5 diagnostic criteria for schizophrenia’s positive symptoms (i.e., hallucinations, delusions, and/or paranoia). This disorder also has two mood dysregulation subcategories; bipolar or depressive types (Assion et al., 2019). Bipolar type is diagnosed if the individual meets the diagnostic criteria for a manic episode as seen in bipolar I disorder (i.e., elevated mood, hyperverbal/pressured speech, irritability, impulsivity, or hypersexuality). Although symptoms of schizophrenia are treated with antipsychotic medications, bipolar disorder is treated with a mood stabilizer (Assion et al., 2019). Because schizoaffective disorder, bipolar type has symptoms of both schizophrenia and bipolar disorder, patients are commonly treated with both antipsychotics and mood stabilizers. Depressive type is diagnosed if the individual meets the diagnostic criteria for major depressive disorder (e.g., depressed mood most or nearly every day, feelings of hopelessness, diminished interest or pleasure in most or all activities, significant weight loss/gain, insomnia/hyperinsomnia, suicidal ideations; APA, 2013). Similar to schizoaffective disorder, bipolar type schizoaffective disorder, and depressive type also requires antipsychotic medication as a form of treatment (Assion et al., 2019). Rather than using a mood stabilizer, however, this subtype will commonly use an antidepressant medication at a therapeutic dose to help alleviate depressive symptoms. Both subtypes of schizoaffective disorder are also accompanied with negative symptoms of schizophrenia and are based treated by psychotherapeutic interventions.

Substance or medication-induced psychosis does not have a known prevalence in the United States; however, about 7% to 25% of individuals with a first psychotic break have been reported to be under the influence of some substance or medication (APA, 2013). Psychotic disorder due to another medical condition presents with an atypical prevalence in the United States at 0.21% to 0.54% (APA, 2013). However, if an individual is over the age of 65 years old, this rates increases to 0.74% compared to younger adults and adolescents. This psychotic disorder is also commonly found in individuals diagnosed with epilepsy (APA, 2013). Schizophreniform disorder has one of the lowest prevalence rates in the United States with percentages 5 times lower than schizophrenia but has more positive prognoses compared to schizophrenia.

Schizotypal (personality) disorder, commonly known as a delusional disorder with various subtypes has a prevalence rate of about .02% in the United States and does not have a significant difference among genders (APA, 2013). Schizotypal (personality) disorder is classified as a psychotic disorder in the DSM-5 because it meets the diagnostic criteria for the negative symptoms of schizophrenia, but does not meet the criteria for the positive symptoms (APA, 2013). An individual diagnosed with this disorder may appear as an eccentric, odd, or isolative individual and may present with a constricted affect. These individuals are typically estranged from their families and/or friends. They may also present with paranoid ideations or “ideas of reference (excluding delusions of reference)” but will not present with any hallucinations (APA, 2013). One famous individual known for being diagnosed with this disorder was John Hinckley, Jr. who attempted to assassinate President Ronald Reagan in 1981 (Miller, 2016). Hickley claimed to be in love with actress Jodie Foster and began stalking her in the late 1970s. Obsessed with winning Foster’s affection, Hickley believed he could prove his worth by attempting to assonate the President of the United States. He began isolating and separating himself entirely from his family and friends. Initially, psychiatrists who interviewed Hickley believed he had schizophrenia, but two psychologists believed he met the criteria for schizotypal (personality) disorder and narcissistic personality disorder (Miller, 2016).

The etiology of schizophrenia and schizoaffective disorders are not fully understood in modern sciences. However, studies do support that higher rates of trauma can lead to higher rates of developing severe mental illnesses (Newman et al., 2010). Newman et al. (2010) evaluated 70 residents of psychiatric inpatient facilities and compared their trauma experiences with their respective differentiating diagnoses. These authors were also interested in testing for comorbidities of meeting diagnostic criteria for posttraumatic stress disorder (PTSD), rates of anxiety, psychosis, and dysphoria. According to these authors, individuals who live with schizophrenia and/or schizoaffective disorders have a much higher likelihood of experiencing violent victimization or non-interpersonal traumatic experiences, compared to the general population (Newman et al., 2010). In addition, Newman et al. found individuals with schizophrenia reported higher rates of anxiety and dysphoria with higher rates of violent victimization.

However, participants reported a significant number of psychotic symptoms with greater prevalence rates of non-interpersonal traumatic experiences. Comparing to individuals with schizoaffective disorders, participants indicated higher rates of experiencing anxiety and dysphoria with significantly higher rates of non-interpersonal traumatic experiences. They also proclaimed significant rates of violent victimization with more psychotic symptoms compared to participants with schizophrenia (Newman et al., 2010). When comparing individuals with PTSD and non-PTSD symptoms, both groups of individuals had an overall 72.9% likelihood of experiencing violent victimization and non-interpersonal traumatic experiences in their lives, and may require frequent acute care.

Emergence of Psychosis

Individuals who live with severe mental illnesses can experience trauma beginning in their childhood (Álvarez et al., 2011). Children who present with early onset symptoms of some mental illnesses may present as strange or as ignoring their families. This can be met with harsh responses in some cultures (Álvarez et al., 2011). According to Álvarez et al. (2011), children who experience abuse are more likely to develop severe forms of mental illness by late adolescence. These authors conducted a cross-sectional study by using 102 participants who are diagnosed with schizophrenia, schizoaffective disorders, and bipolar disorder with psychotic features. The authors used the Brief Psychotic Relative Scale and Traumatic Life Events and Distressing Events questionnaire to assess levels of experienced childhood trauma in their participants (Álvarez et al., 2011). These authors also collected participants' medical records, providing participants' history of social experiences, demographical data, and clinical treatment. According to their research, the authors found nearly 47.5% of their participants have experienced some form of childhood abuse, including mental, physical, emotional, psychological, and sexual traumas. They also found a significance in participants with schizophrenia who experienced childhood abuse were diagnosed nearly 4 years earlier than those with schizoaffective disorders or bipolar disorders (Álvarez et al., 2011). In addition, participants who have experienced childhood sexual abuse were at a 68% likelihood of attempting suicide, while other forms of trauma had a 28.9% likelihood of attempting suicide.

In another study, Zarse et al. (2019) collected archival data from 134 articles using the Adverse Childhood Experiences Questionnaire (ACE-Q) to assess the development of mental illness and diseases in adults who have experience severe childhood trauma. The ACE-Q study supports a higher likelihood of developing mental illnesses, substance use disorder, and medical diseases with a higher number of ACEs (Zarse et al., 2019). Similar to Álvarez et al.'s (2011) study, Zarse et al. found individuals who live with schizophrenia or schizoaffective disorders reported a higher number of ACEs and higher childhood traumatic experiences before adolescence and early adulthood. Zarse et al. suggested further integration of health services are needed to address childhood trauma at early stages of life.

In addition to childhood abuse, adults diagnosed with psychotic disorders or disorders with psychotic features (i.e., bipolar I disorder, with psychotic features or major depressive disorder, with psychotic features), are more susceptible to neglect from their families (Larsson et al., 2012). According to Larsson et al. (2012), adults with schizophrenia spectrum or affective disorders can experience significantly higher incidences of physical or emotional neglect. Physical neglect is defined as a caregiver or parent not providing the basic needs to a child such as food, water, or shelter. Emotional neglect consists of but not limited to consistently disregarding, ignoring, invalidating, or not appreciating an individual’s affectional needs. In this study, the authors gathered 305 participants from three psychiatric hospitals that are diagnosed with schizophrenia spectrum or affective disorders (Larsson et al., 2012). The authors used the Childhood Trauma Questionnaire to measure traumatic childhood experiences. Their results found a high significance with 82% of their participants experiencing one or more traumatic childhood experiences and were more commonly reported from male participants (Larsson et al., 2012). Participants with affective disorders showed higher rates of emotional neglect whereas, those diagnosed with schizophrenia spectrum disorders showed higher rates of physical neglect (Larsson et al., 2012).

One of the distinguishing symptoms in psychotic disorders are hallucinations, mainly auditory and visual. However, there are three other types of hallucinations including: tactile (touch), olfactory (smell), and gustatory (taste). Although both psychiatric and psychological researchers have not discovered a direct link to specific hallucinations and childhood trauma, several studies have been focused on better understanding the emergence of psychotic symptoms in first episodes of psychosis (Solesvik et al., 2016). In a study conducted in Norway, researchers recruited 204 participants who met DSM-V criteria for several psychotic disorders. Solesvik et al.’s

(2016) study emphasized on obtaining participants' background histories including experiences in their childhood and relationships with their families. Participants were between 15–65 years old (mean age = 26.6 years, 43.3% female, and 56.7% male) and were assessed using the Positive and Negative Syndrome Scale (PANSS) to measure symptom severity and were clinically interviewed to gain perspective of their individual histories (Solesvik et al., 2016). Solesvik et al. found significantly high traumatic experiences and organized these experiences into three categories including interpersonal, non-interpersonal, and drug abuse. The study's results indicate of the total number of participants (*n* = 204), 31.5% experienced interpersonal trauma, 16.3% experienced non-interpersonal trauma, and 25.7% experienced childhood drug abuse.

When correlating psychotic symptoms and initial psychotic episodes, Solesvik et al. (2016) found links between specific auditory and visual hallucinations with their participants' childhood traumatic experiences. The authors found specific visual hallucinations such as seeing shadows or changing faces were linked to those who reported significant interpersonal trauma and were seen more frequently in female participants. In contrast, specific auditory hallucinations such as religious-affiliated hallucinations (i.e., being commanded to do harm to others or self-harm by a higher power—God) were reported by participants who had significant non-interpersonal traumas in their childhood (Solesvik et al., 2016). Whereas the results of Solesvik et al.'s study found limited correlations between childhood traumatic experiences and specific hallucinations, the authors' study conclusions provide a significant understanding of how traumatic events may lead to the development of specific hallucinations.

Although childhood trauma may be common in adults with chronic mental illnesses, some adults with mental illnesses may have not experienced trauma at all or may have experienced trauma in their early adulthood (Cohen et al., 2010). Typically, adults diagnosed with schizophrenia receive their diagnosis in their early to mid-20s. Younger adults with schizophrenia typically have higher rates of re-admissions to psychiatric inpatient hospitals than older adults with schizophrenia. Cohen et al. (2010) focused on understanding the etiology and persistence of schizophrenia symptoms and their impact on older adults. In addition, the authors were interested in how trauma impacts positive and negative symptoms of schizophrenia in older adults compared to younger adults. The authors were also interested in comparing rates of psychiatric inpatient hospital admissions in young and older adults with schizophrenia.

Cohen et al. (2010) recruited 198 participants older than 55 years old and were diagnosed with schizophrenia spectrum disorder (SSD) prior to age 45. The authors compared them to random groups of 113 participants in the same age range and do not have diagnosis of schizophrenia. Using the Trauma and Victimization Scale (TVS) to calculate severity of trauma over their lifetime the control group of adults diagnosed with SSD were dichotomized into groups that compared a prevalence of low and high trauma ratings. Their results supported a higher significance of trauma rates for adults with SSD by 55%, with a score of 6 out of 11 items on the TVS compared to the group without a diagnosis of SSD (Cohen et al., 2010). In addition, most participants in the control group shared experiencing trauma prior to age 17 and prior to experiencing positive symptoms (i.e., psychosis). The authors’ finding did not evince a significant difference between psychiatric hospital admissions when comparing young or older adults (Cohen et al., 2010).

Although both men and women can be diagnosed with schizophrenia, the diagnosis has a higher prevalence in men (APA, 2013). However, traumatic experiences can vastly vary between the two genders and may present differently. Although Larsson et al. (2012) stated men with schizophrenia reported significant rates of emotional and physical neglect in their childhoods, women are most susceptible to physical and sexual traumas in their adulthood (Yildirim et al., 2014). Authors of this study were interested in understanding trauma in female adults with schizophrenia, who have not reported experiencing childhood trauma. A total of 70 female participants who were diagnosed with schizophrenia were given three assessments to measure their traumatic experiences; the Traumatic Experiences Checklist, the Positive and Negative Syndrome Scale, and the Calgary Depression Scale for Schizophrenia (Yildirim et al., 2014).

The authors categorized their findings from the Traumatic Experiences Checklist and Calgary Depression Scale for Schizophrenia into five categories, such as 81.4% of participants reported physical abuse, 78.6% of participants reported emotional abuse, 55.7% of participants reported emotional neglect, 28.6% of participants reported sexual harassment, and 24.3% of participants reported sexual abuse (Yildirim et al., 2014). In addition, according to the Positive and Negative Syndrome Scale, female patients who experienced unwanted sexual attention as adults reported a higher prevalence of experiencing hallucinations, blunted affect, emotional withdrawal, hostility, anxiety, and affective lability (Yildirim et al., 2014). In addition, female participants reported sexual abuse and/or sexual harassment in adulthood and had difficulty in delaying gratification items on the Positive and Negative Syndrome Scale (Yildirim et al., 2014).

Additional Correlates of Mental Illness

Although there is ample research to support associations between childhood trauma and the development of mental illnesses, there is limited research finding associations between childhood trauma and the development of psychosis. In a study with 345 participants, ages 18–54 years from community mental health centers, researchers tested for correlations between first episodes of psychosis, substance use, and childhood trauma (Tomassi et al., 2017). Participants were assessed using the Childhood Experience of Care and Abuse Questionnaire and the Cannabis Experiences Questionnaire. Researchers separated types of abuse by sexual abuse (e.g., "unwanted sexual experience occurring more than once; the perpetrator touched the child's genitals, forced the child to touch the perpetrator's genitals, or sexual intercourse") and physical abuse (e.g., "repeated exposure to physical violence from a parental figure before age 16"; Tomassi et al., 2017, p. 152).

The authors also categorized substance use into three types of substances: cannabis, cocaine, and heroin. Of the total population, 41.7% of participants, mostly males (58% of $n = 345$) reported experiencing psychotic symptoms related to severe sexual abuse before age 16, 15.6% reported experiencing psychotic symptoms related to severe physical abuse, and 22% reported experiencing psychotic symptoms related due to loss/separation of family members (Tomassi et al., 2017). Additionally, 68.2% of participants who experienced psychotic symptoms related to sexual abuse reported lifetime cannabis use, 53.5% experiencing psychotic symptoms related to physical abuse reported lifetime cannabis use, and 53.5% experiencing psychotic symptoms related to loss/separation of family members reported lifetime cannabis use (Tomassi et al., 2017). Authors of this study did not find any significant correlation between childhood trauma and psychosis with cocaine (16% reporting lifetime usage) or heroin (5% reporting lifetime usage). Statistically, the authors found a significant correlation in experiencing first episodes of psychosis in participants who reported severe sexual abuse and lifetime cannabis use (Tomassi et al., 2017).

Although research does not evince a definitive correlation between substance use and psychotic disorders, several research articles do examine associations between types of childhood abuse and substance use within individuals who have psychotic disorders (Rabinovitz et al., 2019). In addition, individuals diagnosed with psychotic disorders have higher likelihoods of being hospitalized several times throughout their lives and several of these hospitalizations are linked to substance use. According to Rabinovitz et al. (2019), specific abuse types and patterns can be found in patients with schizophrenia. For this study, the authors examined 2,147 participants from sexual assault support centers and assessed for those who have confirmed diagnoses of schizophrenia. Of the 2,147 participants, 117 had diagnoses of schizophrenia and history of having psychosis diagnoses prior to being diagnosed with schizophrenia. Rabinovitz et al. assessed for correlations between sexual assault and substance use within individuals who live with schizophrenia. Medical records revealed sexual assaults at younger ages were reported from birth to 6 years post sexual assaults (Rabinovitz et al., 2019). The study's results support that 27% of the female participants and 16% of the male participants reported severe substance use and sexual assaults and were diagnosed with schizophrenia.

Specifically, female individuals with schizophrenia had higher prevalence rates of experiencing sexual assaults at younger ages compared to males, and males had higher rates of substance use compared to females (Rabinovitz et al., 2019).

Individuals with more severe forms of mental illness have higher likelihoods of developing substance use disorders, as comorbid diagnoses (Hartz et al., 2014). According to the National Survey on Drug Use and Health, researchers found adults with more severe mental illnesses have a 36% likelihood of smoking cigarettes, whereas, adults without a mental illness have a 21% prevalence of smoking cigarettes. With individuals who have schizophrenia, 35% of individuals in this survey reported using illicit drugs 10 or more times in their lives (Hartz et al., 2014). Individuals surveyed with schizoaffective disorder, bipolar type reported using illicit drugs at 54% and at 45% for individuals diagnosed with schizoaffective disorder, depressive type. When comparing these numbers to the general public, 7%–18% of individuals without a severe mental illness report using illicit drugs 10 or more times in their life (Hartz et al., 2014). The rationale of this study argue adults with chronic mental illness more likely to use substances compared to those without mental illness. According to the National Institute on Drug Abuse (NIDA, 2020), there are several contributing factors to the etiology of substance use disorders (SUD) in adults with psychotic disorders. One of the primary causes for developing an SUD is to relieve emotional pain the individual is experiencing. For adults who live with mental illness, a typical causation of developing an SUD is to relieve emotional pain commonly caused by traumatic events in their life, and to not take prescribed psychiatric medications due to impairing side effects. Another common cause of development is genetics such as a family history of substance use and/or being raised in an environment that have people actively using substances, which can be traumatic (NIDA, 2020). Therefore, it is imperative to address emotional pain, process any potential traumatic experiences, and develop healthy coping skills for stress reduction may reduce the likelihood of developing an SUD.

Traumatic Life Experiences

The Adverse Childhood Experiences (ACEs) questionnaire has been used in the last 25 years to measure childhood traumatic experiences and impact of these experiences in adults. In addition, the ACEs have been used to predict likelihoods of committing criminal offenses and psychiatric inpatient hospitalizations (Booth & Stinson, 2015). The ACEs categorizes trauma in adversities such as: physical abuse, sexual abuse, household dysfunction, and emotional or verbal abuse. Booth and Stinson (2015) administered the ACEs questionnaires to 211 forensic psychiatric participants and archival data was used to gather information about arrests, incarcerations, treatment, and earlier incidences of offending. Of the total participants, 80% or about 169 individuals were male and 18% or about 42 were female. The authors' results support a significance in males having higher ACE scores compared to females. In addition, males reported higher rates of arrests, incarceration, and psychiatric inpatient hospitalizations compared to females. Therefore, supporting a correlation between criminal outcomes and higher levels of experienced childhood trauma (Booth & Stinson, 2015).

Additional ACEs studies have been used to predict violence in the community or psychological symptoms in younger to late adulthood (Shin et al. 2017). Shin et al. (2017) used 336 participants, ages 18 to 25 and performed a latent class analyses to identify patterns within a younger group of adults and number of ACEs. The authors focused specifically on childhood maltreatment, household dysfunction, and community violence. Using multiple linear and logistic regression models, the authors used ACE scores to predict associations between young adulthood outcomes and alcohol, tobacco, drug dependence, and psychological symptoms. The authors found their strongest significance with higher ACEs in household dysfunction and community violence at 56% of the total group reporting exposure to violence from younger ages. Additionally, Shin et al. found higher ACEs were linked to higher alcohol-related problems and having more severe psychopathology in adulthood. Lower ACEs showed higher prevalence rates of tobacco use but lower alcohol/drug related issues or less severe psychopathology (Shin et al., 2017). These statistics reinforce the importance of addressing traumatic life experiences at younger ages to reduce likelihoods of developing substance use disorders and/or more severe psychopathology.

Treatment

Treatment can vary depending on the clinical setting and the individual's diagnosis. For example, treatment in an inpatient psychiatric setting will place greater focus on managing symptoms with medication and provide short therapeutic interventions to strengthen awareness of the symptoms. Outpatient care maintains medication management and provides long-term therapeutic interventions to treat symptoms and process trauma. Antipsychotic medications are one of primary treatments for the majority of psychotic disorders and in some cases of clinical depression, anxiety disorders, and PTSD (Joshi et al., 2018). Although disorders such as schizophrenia require antipsychotic medication(s) as its primary source of treatment, schizoaffective disorder requires either a mood stabilizer or antidepressant in addition to the antipsychotic medication (Murru et al., 2011). Mood stabilizers are used to treat manic symptoms of schizoaffective disorder, bipolar type and antidepressants are used to treat depressive symptoms and suicidal ideations of schizoaffective disorder, depressive type. Both schizophrenia and schizoaffective disorder are chronic psychotic disorders and often have a negative or low prognosis. Medication adherence is often complicated for the individual due to the metabolic and/or physiological side effects from the medications. Some side effects of antipsychotic medications include weight gain, hypertension, hair loss, tardive dyskinesia, akathisia, incontinence, and constipation (Kumar et al., 2017). Although psychotropic medications are used to treat psychotic or mood dysfunction symptomology, deeper psychological challenges such as trauma and substance use cannot be easily treated with medication.

Although some overt challenges of medication anti-adherence are observed in patients with mental illness, other challenges may be more ambiguous. According to Cabarkapa et al. (2020), patients who are frequently dependent on psychiatric inpatient care struggle with homelessness and chronic loneliness. Without ample support, most adults with mental illnesses will only continue to struggle and typically suffer in silence. Cabarkapa et al. interviewed 250 psychiatric patients who were admitted to inpatient hospitals several times a year. Of the total participants, 159 participants could not sustain on their own for more than 6 months, and the longest reported time participants reported of not being hospitalized was 2 years (Cabarkapa et al., 2020). Participants reported their challenges were the result of their inability to acquire a job, independent housing, and community support. In addition, significant rates of trauma were reported among all participants typically beginning in early adolescence (Cabarkapa et al., 2020).

Therapeutic interventions such as interpersonal skill building, object-relational development, and awareness of needs can address feelings of loneliness, help develop healthy coping skills, address their needs, learn and enforce healthy boundaries, and management their flight/fight/freeze responses.

Psychotherapy is the primary treatment used by psychologists to address psychological challenges such as trauma. Eye movement desensitization reprocessing (EMDR) therapy is one of the most effective forms of treatment for trauma. However, although EMDR is commonly used to treat people without psychotic disorders, modified approaches of EMDR have been studied to address individuals with PTSD and psychotic features (Van den Berg & Van der Gaag, 2012). On average, EMDR sessions for individuals who do not present with psychotic symptoms can see results in between 1 to 3 sessions. Van den Berg and Van der Gaag (2012) recruited 22 participants who had a psychotic disorder and a comorbid PTSD diagnosis. The authors conducted six sessions of EMDR with an adapted treatment approach to minimize overwhelming internal stimuli (i.e., hallucinations). After six sessions of EMDR, a significant number of participants who met the criteria for PTSD (22.7% of $n = 22$) saw improvement in anxiety, depression, self-esteem, and a reduction in psychotic symptoms (e.g., hallucinations and delusions; Van den Berg & Van der Gaag, 2012). However, the six EMDR sessions did not improve paranoid ideations or sense of hopelessness. Therefore, the overall sessions had a significant improvement in overwhelming emotions related to traumatic experiences.

Another form of treatment commonly used to treat several psychological disorders is cognitive behavioral therapy (CBT). CBT has had a great impact on treating adults with psychotic populations. Specifically, cognitive behavioral therapy for psychosis (CBT-p) focuses on addressing negative symptoms within patients who live with schizophrenia or schizoaffective disorders (Belanger et al., 2018). CBT-p focuses on thought processing and how this can impact an individual's feelings and behavior. According to these authors' research, unaddressed negative symptoms increase frequency for positive symptoms within this population. Therefore, processing symptoms such as lack of pleasure in day-to-day activities (i.e., anhedonia), thought disorders, or feelings of wanting to isolate are imperative in CBT-p (Belanger et al., 2018).

According to Kumar et al. (2017), psychotherapy cannot treat positive (i.e., psychotic) symptoms of chronic mental illnesses such as schizophrenia. Psychotherapies such as CBT are used to treat long-term psychological issues the individual may have experienced throughout their lives. According to Williams et al. (2014), CBT's effectiveness has been seen within individuals receiving outpatient treatment in the community, but there is limited research on CBT's effectiveness in psychiatric hospitals. In this study, the authors tested primary and secondary outcomes for CBT interventions with 27 male forensic patients. All participants were assessed using the Scale for the Assessment of Positive Symptoms, the Scale for the Assessment of Negative Symptoms, and the Psychotic Symptom Rating Scales to measure primary outcomes (Williams et al., 2014). The authors used CBT interventions on participants to address interpersonal functioning and to measure interpersonal issues such as trauma for secondary outcomes. Results of this study support a significant reduction in negative symptoms of schizophrenia using CBT interventions compared to non-CBT treatments. A reduction in symptoms included: a less flat affect, less anhedonia (e.g., inability to feel pleasure), less alogia (e.g., diminished/poverty of speech), and avolition (e.g., decreased motivation; Williams et al., 2014).

In addition, CBT-p can address aggression which tends to be a prevalent emotion seen in adults who live with schizophrenia and schizoaffective disorders. Aggression is a common misrepresentation for fear in this population, which may be triggered by traumatic experiences (Belanger et al., 2018). Subsequently treating trauma in this sensitive population may reduce the impairment of negative symptoms (Nowak et al., 2016). According to Nowak et al. (2016), CBT-p interventions such as cognitive restructuring, automatic thought journals, and role playing has a significant impact on treating trauma and negative symptoms of adults who live with schizophrenia. Although disorders such as schizophrenia and schizoaffective disorders are chronic illnesses, recovery is variable depending on the individual's response to therapy (Nowak et al., 2016). Nowak et al. reviewed 50 studies from PsychINFO which compared interventions used from CBT for psychosis and recovery-focused CBT. Of the total studies reviewed, 35 studies used a CBT for psychosis approach and 15 studies used the recovery-focused CBT approach. The authors concluded both methods were effective in treating traumatic experiences in adults with schizophrenia, but recovery rates were difficult to predict, specifically in populations with schizophrenia compared to other psychological disorders.

Another supporting study used combined databases from MEDLINE and PsychNET, researchers were interested in finding outcomes for implementing CBT interventions on individuals who live with schizophrenia (Dumont et al., 2018). This study also looked at future integration of these psychosocial interventions in forensic psychiatric settings and overall healthy living in adults with schizophrenia. From 24 total studies found on MEDLINE and PsychNET, researchers found 18 different psychosocial interventions. Using a quasi-experimental design on their control group, participants saw improvement in problem solving and obtaining a better understanding of their diagnosis (Dumont et al., 2018). Seven studies reported significant positive outcomes in learning how to reduce violence, aggression, and recidivism. The authors found the majority of these psychosocial interventions, incorporated CBT techniques with particular focus on social cognition, social skills, problem solving, emotion management, and neuro-cognition (Dumont et al., 2018).

Limitations to Treatment

Although there are various treatments to intervene with chronic mental illness, there are significant limitations that require modification. According to Johnson et al. (2019), three major limitations to the addressing trauma in adults with mental illness are violence risk measurements that are insensitive and bias toward violence classification, data that lack spatiotemporal contiguity, and the use of cross-sectional data to understand human differences. Johnson et al. recruited 3,000 participants to measure self-reported violence in populations that have substance use and psychotic disorders. The study reported nearly 1,500 reports of participants observing violence in their lives. In addition, the study found time lags within the amount of reporting violence in this population. The authors attributed this to participants reporting their perception of violence as defined subjectively based on their experiences. Results of this study support that violence risk assessments may need to be revised to be less specified in the questions to prevent a patient feeling the question is not applicable to them and their worldview.

The effectiveness of treatment within populations that live with chronic mental illnesses is greatly neglected. Specifically, within individuals who live with disorders such as schizophrenia, schizoaffective disorders, and bipolar disorders. According to Ahmed et al. (2015), family support is an aspect that significantly lacks in predicting positive treatment outcomes. This includes providing psychoeducation about the illness not only to the person who lives with it, but to the families impacted by their loved one's illness. Ahmed et al. used a quasi-experimental design to collect data from their participants. The authors used short questionnaires to gather data to better understand what impacts medication adherence and psychosocial treatments within populations that live with mental illness. The study's results supported higher positive prognoses when families were included in this process and increased adherence to treatment. Therefore, it would be imperative to first understand how the individual living with mental illness perceives treatment, so their families can be better educated and participate in their loved one's treatment.

In another study, Conway et al. (2020) used a quantitative classification system to categorize mental illness into a hierarchical structure for seeking treatment. The rational of this study focused on understanding the development of mental illness and how adults who have mental illness seek treatment. Conway et al. emphasized the importance of establishing relational factors of trauma and mental illness and the ability of the individual to pursue treatment. The authors noted one significant limitation to understanding how adults who have mental illness seek treatment is the assessment methods of individuals who have mental illness. The study suggested further research is needed to construct assessment methods that limit bias of the individual and their subjective life experiences.

Theoretical Roots of Psychotherapeutic Treatment

As opposed to using therapy modalities such as CBT, psychodynamic therapy focuses on the influence of childhood experiences and how these experiences have developed or influenced functioning in adulthood (Shedler, 2010). A psychodynamic therapist puts emphasis on how the individual responds to transference and countertransference (Kovács et al., 2020). Psychodynamics places importance on understanding psychiatric symptoms and psychological distress through enhancing corrective emotional responses to trauma. Psychodynamic therapy places an emphasis on understanding mental and emotional processes without placing greater understanding on behavior. CBT typically follows a structured approach with a specific goal to resolve any internal conflict within the individual (Shedler, 2010), whereas psychodynamic therapy places greater emphasis on free association to allow the individual to explore unconscious thoughts. Although traditional psychodynamic practices focused on the patient not seeing the therapist, modern psychodynamic therapy uses the “two chairs” method and facing each other. Research supports that the face-to-face method helps build rapport between the therapist and patient as well as overall success (Shedler, 2010).

In addition, the overall goal of this intervention is to replace unresolved conflict with a more positive ending (Kovács et al., 2020). Psychodynamic therapy has a set of goals in which a therapist will outline throughout treatment to see higher likelihoods of success (Shedler, 2010). The first goal is to have the client obtain their own self-awareness and recognizing themselves as an individual. The second goal is invoke further understanding of the individual’s thoughts, feelings, and beliefs (Shedler, 2010). This will assist the individual to find associations between past experiences and current thought processing. The end goal of this treatment method is to assist the individual resolve the unresolved internal conflicts and significant moments of the individual’s past (Shedler, 2010). Psychodynamic therapy also places greater emphasis on finding reoccurring patterns within the individual’s life. For instance, helping the individual to become privy of painful or self-defeating patterns and the individual’s inability to not cease this way of thinking. This can be seen in an individual who will sabotage themselves when they are about to achieve success in a goal. The individual may fear success because of a past event that caused harm or pain after achieving success (Shedler, 2010).

When comparing psychodynamics efficacy to other therapeutic modalities, psychodynamics placed greater emphasis on confronting and processing past traumas or experiences that have not been processed (Steinert et al., 2017). Steinert et al. (2017) used a meta-analysis design to correlate outcomes between CBT and psychodynamics in treating several different psychological disorders. The authors used the Randomized Controlled Trial Psychotherapy Quality Rating Scale (RCT-PQRS) to assess outcomes for interrater reliability and validity. Steinert et al. reviewed 23 randomized controlled trials with a total of 2,751 participants. Their results support a strong correlation in psychodynamics showing more significant outcomes in resolving symptoms of depression, anxiety, eating disorders, Cluster C personality disorders, and PTSD, whereas CBT proved greater impact on substance-use disorders and was more effective in a group format compared to psychodynamic therapy being an individual therapeutic approach (Steinert et al., 2017).

A potential misconception is the past does not go beyond the past, that it cannot affect you in the present or future. However, empirical research on psychodynamics has shown significance in addressing past experiences (Steinert et al., 2017). The goal of confronting past experiences is to address how a person's past has affected their present and future (Shedler, 2010). In addition, psychodynamic therapy places focus on how the past can impact interpersonal relationships. Attachments and relations to objects or other people can be greatly impacted if the individual is not able to appropriately adapt to changes within interpersonal relations (Shedler, 2010). This can particularly become problematic if the individual feels their emotional needs are not able to be met. Emotional needs of individual is imperative for healthy human functioning and can have devastating ramifications if these needs are not met. Psychodynamic therapy also addresses the importance of emotions and exploring unprocessed emotions (Shedler, 2010).

For individuals who have experienced neglect as a child may find emotions or feelings are a threat, but may not recognize why they feel troubled or threatened by these emotions (Kovács et al., 2020). This can be observed in therapy sessions by an individual who misses or is late to sessions and is being evasive after confronting distressing thoughts or feelings surrounded by unprocessed emotions (Shedler, 2010). Some individuals may describe living in a fantasy life where the person has not experienced difficulties in their past, which commonly leads to dissociation. Bringing this fantasy life into reality can be challenging and cause further distress to the individual if not done carefully and without a safety plan already being established (Shedler, 2010).

This study will incorporate the role of cultural diversities such as: ethnicity/race, gender, SES, and spirituality/religion. According to Schwartz and Blankenship (2014), these demographics influence the development of trauma and chronic mental illnesses. As mentioned previously in Schwartz and Blankenship's study, chronic psychotic disorders such as schizophrenia and schizoaffective disorders are mostly commonly diagnosed in African American and Latino/Hispanic males in the United States. These diagnoses are also commonly seen in communities that have lower socioeconomic statuses, education resources, and lack of medical services. These populations also report higher rates of childhood abuse such as physical abuse and neglect compared to any other race in the United States (Schwartz & Blankenship, 2014). This proposed study may provide further evidence to support healing in communities that have significantly higher disparities. Disparities in the community generalize methods of assessing violence and what is considered a significant violent risk (Johnson et al., 2019). Further research is needed to individualize a traumatic experience, the individual's worldview, and how clinicians can provide the best optimal care to patients who have mental illnesses.

Worldview as a Result of Trauma and Mental Illness

A worldview is defined in the Merriam-Webster dictionary as "a comprehensive conception or apprehension of the world especially from a specific standpoint" (Merriam-Webster's Collegiate Dictionary, 1999). Standpoint is a particularly important aspect of this definition since human beings define the world around them from their subjective experiences. Although trauma overtly impacts the way in which people view the world around them, trauma is often underreported (Mauritz et al., 2013). According to Mauritz et al. (2013), one crucial limitation to their study and of the 30 studies they reviewed was the unquantifiable number of adults who live with mental illness, underreporting or not reporting trauma. Therefore, clinicians are not able to make as significant of an impact on processing through trauma with adults who live with chronic mental illness. This may imply an already darkened worldview may only become more abysmal for the individual suffering with their traumatic experiences and are further inhibited by mental illness.

As trauma can have such an influential impact on an individual's worldview, individuals who live with mental illness may face increasing resistance from clinicians to process their clients' worldview and how they differ from their own (Mauritz et al., 2013). According to Schlitz et al. (2010), the development of individual worldviews begin in the earliest stages of childhood. Worldviews are defined by how we learn to categorize, discriminate, and generalize our experiences in life. Schlitz et al. suggested our worldviews help formulate our values, beliefs, attitudes, and our idea of reality. In addition, our worldviews help us to make changes in our lives based on our past and present life experiences, which may alter future experiences (Schlitz et al., 2010). In another study, Webster and Deng (2015) found traumatic life experiences can affect an individual's worldview both negatively and positively. Using a trauma narrative method, Webster and Deng's study had a total of 320 participants (*n* = 320, 130 males and 190 females). The authors of this study took the trauma narratives written by their participants and aimed to understand how wisdom, intrapersonal strength, worldview, and posttraumatic growth were impacted by traumatic life events. Although decades of research support a direct correlation to the development of mental illness as a result of trauma, limited research has been conducted to understand positive impacts of trauma (Webster & Deng, 2015). Webster and Deng found traumatic life events impacted worldview and how growth in wisdom can be limited by posttraumatic growth and intrapersonal strength.

By gaining a broader understanding of the individual seeking behavioral health services, mental health providers can include a multifactual and diverse dynamic to a person's treatment plan for recovery. For example, by incorporating more spirituality and religion into treatment for patients who rely on these qualities, may find comfort in regards of their trauma and/or mental illness. According to Starnino (2016), recognition of spiritual and religious beliefs are effective coping skills used in people during times of distress. Part of some people's worldviews include their sense of spirituality and religion. For instance, an adult expressing religious pre-occupied thoughts or expressing their direction connection to God might be seen to some as delusional thinking or religious auditory hallucinations (Starnino, 2016). It is imperative to recognize people all around the world state frequently that God or another deity speaks with them, or they speak to God or another deity. Although a person with schizophrenia may say they speak with God or God speaks with them, it is the clinician's responsibility to carefully distinguish between psychopathology and spiritual/religious beliefs. By incorporating this into treatment, individuals who depend on spirituality/religion may feel validated in their worldviews and may feel more inclined to participate in their treatment.

Incorporating religion and spirituality may also provide clinicians with an understanding of how clients or patients experiencing psychosis may use religion as an escape. According to Sedláková and Řiháček (2019), individuals experiencing chronic psychosis may develop a spiritual emergency experience. This experience is characterized by the individual being impacted by psychotic symptoms and using religious beliefs to mitigate or eliminate their experiencing symptoms. By using this method, the individual may be able to return a state of functioning homeostasis (Sedláková & Řiháček, 2019). The religious beliefs may be identified as accepting the symptoms as a personal sense of meaningless to a greater calling of their life. Rather that the experience may be a potential bid from God to adopt a new perspective. Sedláková and Řiháček interviewed 13 participants who experienced spiritual emergency episodes while in a psychotic state and carefully assessed what connections or disconnections they felt from the world around them. A significant theme constructed from this qualitative study was how the spiritual emergency experience gave exposure of previous life events or experiences. Coping skills was a subtheme to this theme and the study found participants with poor coping skills experienced a greater impact on the worldviews (Sedláková & Řiháček, 2019).

Study Rationale

The rationale for this study was to understand how adults with chronic mental illnesses perceive treatment of their symptoms. In addition, this study's goal was to identify areas of behavioral health that would benefit from any adaptations based on a patient's perspective. By understanding how one defines their worldview and perception of life, may provide clinicians the opportunity to normalize skepticism, fear, and resistance to participate in treatment. Potential reasons for individuals underreporting trauma is shame, fear, guilt, and feelings of not being validated (Dunn et al., 2018). According to Dunn et al. (2018), early exposure in childhood can lead to an inability to report the trauma sooner than later. However, the more time that goes by from the trauma exposure, the higher risk of developing emotional dysregulation increases (Dunn et al., 2018). Specifically, adults in this population who are inhibits by biological impairments of mental illness are at an even large disadvantage to comfortably disclose their trauma exposure. However, by understanding their worldviews from an individual perspective, clinicians may be able to better tailor treatment plans that have great impact on healing from trauma.

An additional rationale of this study was to develop a more effective way of educating mental health professionals on how current treatment is being received by their patients, what aspirations of improvement to the field can be implemented, and how mental health providers can increase overall optimal care to a population of adults who too often suffer in silence. As mentioned previously in Conway et al.'s (2020) study, increasing relationship between clinicians and patient are paramount to healing and recovery. Some significant limitations to current treatment methods consists of excluding aspects of one's life that are crucial to the individual. This study provided viable options to increase awareness of how mental health services are delivered and how clinicians address their patients based on these participants' lived experiences. This study can be used to promote further participation in treatment and inform providers to address the needs of their patients.

Chapter 2: Research Methodology

Philosophical Worldview

This study will use a phenomenological worldview to better understand this population. This worldview is defined by giving meaning to our experiences and understanding how they are based on our ways of living. This worldview was initially conceptualized to bring logic into psychology similar to bringing logic into hard sciences such as chemistry and physics (Bartlett, 1969). Phenomenology brings into question the logic in which something is analyzed. For instance, a chemist analyzing the molecular structures of an element. By introducing a new understanding to interpret the understanding of the element's structure, the concept of logic is now interrupted (Bartlett, 1969). In psychological practices, phenomenology offers a further understanding of the person's mental health without quantifying the experiences they have had.

The philosophy of phenomenology originates from Husserl, a German philosopher (Smith, 2018). Husserl established the school of phenomenology taking concepts from Plato, Aristotle, Descartes, and Hindu/Buddhist philosophies. Using philosophical concepts of perception, thought, and imagination conceptualized the idea of mental phenomena. In addition, using Hindu and Buddhist philosophies such as meditation allows an individual to become more privy of their consciousness (Smith, 2018). Several forms of phenomenology were developed since Husserl's conception of the philosophy. One imperative form of phenomenology is realistic, the idea that consciousness and intentionality are occurring in real world time with the concept that a large part of external consciousness is not brought into internal consciousness (Smith, 2018). Bartlett (1969) argued this concept of realistic phenomenology give the possibility of throwing phenomenon into question of its logical use. By understand the conscious thoughts, perceptions, and imaginations of the person, you begin to question the logic of their mental health. By questioning this logic, it gives the person the ability to understand what is or is not logical to their thinking (Smith, 2018).

This worldview is imperative to this study because it aims to obtain further understanding of how people who live with mental illness and trauma perceive life and what influences their traumatic experiences have had on their treatment. By developing themes and subthemes from participants' responses, this study may be able to develop future effective methods to increase positive treatment outcomes and help clinicians customize a treatment plan to the individual's worldview.

The purpose of this study is to obtain further understanding of how adults who live with chronic mental illness perceive their treatment and what adaptations could be made to the field of behavioral health. Clinicians write treatment plans to develop goals of symptom improvement and overall emotional healing for the individuals they work with. In inpatient psychiatric settings, treatment plans place greater emphasis on psychiatric symptom management. Outpatient settings focus on medication management and other psychological difficulties such as trauma or coping skills for these experiences are not incorporated at a greater length.

These treatment plans do not include an in-depth culturally diverse understanding of the person's history and how this has developed their worldviews. By including a multicultural approach to developing an individual's treatment plan, clinicians can take into consideration how cultural norms, religious/spiritual beliefs, and family system expectations (Davis et al., 2018). Recent research studies over the last decade have been studying how therapists can better integrate multiculturalism into psychotherapy. Specific validations such as cultural humility and cultural comfort have been a significant area of focus within this research (Davis et al., 2018). This study is also aiming to understand how including articulated details of a person's race, ethnicity, religion, and other cultural norms can build a stronger therapeutic alliance with the individuals and care provider. This will be emphasized by further understanding the person's worldview and these qualities of life have work for them or against them in their mental illness and traumatic experiences.

According to Wilson et al. (2018), understanding the worldview of patients in greater depth will help clinicians and medical professionals ensure better cultural awareness and embracing more helpful forms of practice with marginalized populations. Another aim of this study was to understand how these attributes of their mental illness and trauma have a direct impact on them. This opportunity is giving the individual the ability to freely share their life experiences without a goal to resolve the problem with a quick solution. Much of the therapeutic alliance between the clinician and patient is based on validating their experiences. By understanding their history of trauma and mental illness, we can better accept their worldview as acceptable based on their lived experiences.

By conjoining the multicultural diversities of the individual's worldview, clinicians may be able to help patients feel like they have a greater influence in their treatment planning. This may also help clinicians provide more optimal care for the patient who is living with their mental illness and trauma. An additional goal of this research is to understand how patients have made life decisions as it relates to their trauma and mental illness histories. Specifically, if the individual feels like they had a choice in their life (i.e., how to handle their own mental health) decisions or if they feel like the decisions were made for them.

Research Questions

The following questions were focused on in this study by incorporating worldview into understanding how an individual who lives with chronic mental illness perceives treatment. The first question was: What has treatment consisted of for the individual and how they feel the treatment has or has not worked well for them? The second area of focus was to find what changes can be made in the delivery of mental health services according to a patient's perspective as opposed to a provider's perspective. These potential results may provide a more thorough understanding of what this populations' need are in their mental health care by incorporating multicultural worldviews into treatment plans to ensure a multi-factual approach.

Population and Sample

This study included seven adults ages 18 or older from a psychiatric setting who have been diagnosed with a chronic mental illness which may include but not limited to: schizophrenia spectrum and psychotic disorders, bipolar and related disorders with a history of psychotic features, major depression disorders with a history of psychotic features, trauma disorders with a history of psychotic features, personality disorders, and substance use disorders with a history of psychotic features. According to the Center for Disease Control and Prevention, a chronic mental illness is a psychological disorder persistent in the individual's life and limits the individual's psychological functions. These diagnoses should have diagnosed by a physician (i.e., psychiatrist), psychiatric nurse practitioner, or psychologist. All participants must be psychiatrically stabilized and have sufficient oral language expression to participate in the interview. This should be determined by the setting's psychiatrist, psychologist, or therapist. Participants' identifying information such as medical record numbers, social security numbers, and first/last names, will not be used in this proposed study. Participants were assigned a letter and number to represent their identities (e.g., P1, P2, and so on).

This study was proposed to a psychiatric outpatient clinic and was approved to recruit participants from their organization. Formal data collection began once full approval was granted from Northwest University's Institutional Review Board (IRB). Once all overseeing boards approved this study, therapeutic providers at the clinic were fully informed about this research prior to meeting with participants. This was to ensure participants' overall safety and confidentiality, to obtain permission for recruitment, and the ability to have resources available in the event a participant became distressed by this study.

Recruitment was done by speaking with individual clinic mental health providers to advertise the study to their clients in the clinic. Previous clients of this researcher were also recruited for this study. Given the symptomology of most chronic mental illnesses, participants may be distressed by sharing their life stories with this researcher. Rapport is an essential aspect of providing treatment to this population and requires some sense of trust (Cabarkapa et al., 2020). This population typically struggles with trusting others due to their diagnosis and/or traumatic experiences. The participant may feel more comfortable sharing their life experiences and perception of treatment if their experiences are validated in a safe environment.

Research Design and Methodology

This study used a qualitative approach by using an interview method with two interview questionnaires. Questions were structured to understand the individual's demographics (see Appendix B) and five open-ended structured questions to understand their perception of treatment and their life experiences (see Appendix C). According to Creswell (1994), qualitative studies are forms of research using an inquiry process of understanding human and social problems, by developing a complex but holistic understanding of a group of individuals, and representing this data in a non-numerical, word-based format. This study used a phenomenological worldview to better understand this population made meaning of their lived experiences. Follow-up questions were asked as needed to gain further explanation or clarification on participants' responses. Sensitivity was used in these questions to minimize feelings of discomfort, shame, or distress. The interview protocol was structured this way to prevent evoking emotional discomfort in the participant. In addition, the participant was reminded they do not have to answer any question that makes them feel uncomfortable to answer and was reminded they may cease participation at any time, for any reason.

The study was submitted to Northwest University's Institutional Review Board (IRB) to carefully outline the study methodology, study design, and protection of participant information. In addition, consent forms (see Appendix A) were given to participants to ensure that their participation was voluntary and that the participant fully understands what the study would entail. Consent forms also ensured participants' identity and information are kept confidential by not using any identifying information of the participant in the study. Similar to all important legal and medical documentation patients receive while they are in treatment, this consent form was used as a personal copy for them to understand confidentiality and their participation is completely voluntary, not compelled. Participants were informed of the limits to confidentiality such as: the participant expressing potential harm to themselves, harm to others, or endangering a child, developmentally disabled individual, or vulnerable adult. Following the American Psychological Association's (APA) ethic guidelines to integrity of research, this study attempted to minimize any harm to participants. The research study was designed in such a way to carefully balance the potential benefits from the potential risks to participants.

This study attempted to minimize harm such as a limited length of the interview (i.e., to prevent potential fatigue feelings), framing the questions in an open-ended format (i.e., to prevent a suggested outcome or response to the question), and emphasizing participants may decline to answer any question without penalty (i.e., to prevent pressure to answering a question and causing feelings of doubt). This researcher wanted to reinforce the interview would be conducted in a safe space without judgment on them and reinforce their ability to cease participation if they became uncomfortable. The psychiatric organization and participants were provided with documentation which clearly outlined any information obtained from participants would be kept confidential. The information gathered from participants such as any information that may lead to identification of the participant (e.g., name, treatment location) were kept separate from participants' responses.

Data Collection Process and Procedures

Once the study was accepted and approved, I read the consent form to participate to reinforce participants' understanding of what they are consenting to. In addition, participants were given the opportunity to ask any questions prior to the study being conducted. All participants were then given an opportunity to participate individually in grounding activities (i.e., mindfulness techniques such as diaphragmatic breathing) prior to the study beginning. Participants were asked the demographics questionnaire first and then the five open-ended interview questions. As previously mentioned, qualitative studies provide validity through direct quotes to produce themes and subthemes of the study. Participants were informed a method of collecting direct quotes will be used. Microsoft Word was used through the encrypted Northwest University Microsoft 365 Office system to record and transcribe interviews, which did not use audio or video recordings. Interviews took on average 45 minutes to one hour and was done using the HIPAA compliant videoconferencing program, Doxy.me.

Frequent check-ins were made with the participant after every question to make sure the participant was not feeling overwhelmed and was still willing to participate. If the participant expressed concerns or disinterest in continuing participation, the participant was given the opportunity to cease participation and their information was not used. In the event a participant felt triggered, distressed, or uncomfortable about sharing their personal histories of trauma and/or experiences, appropriate resources were be provided to participants in the consent form as well as by me. Examples include speaking with their therapist if they are a current client in the clinic or they were also be provided a crisis hotline number if they became too overwhelmed.

In addition to the interview questions, two other forms of data collection were used in the study such as behavioral observations and field notes. Field notes have been a crucial component in qualitative studies since the early 20th century (Phillippi & Lauderdale, 2018). Field notes not only record behavioral observations of the participant, but they provide valuable insights and queries that can prove valid and needed when addressing the research questions of the study. In addition, field notes assist in providing subsequent analyses such as metasynthesis (Phillippi & Lauderdale, 2018). Metasynthesis is a secondary analysis of data that aids the researcher in providing has much validity as possible for the research study. Both behavioral observations and field notes can be helpful in providing subthemes to a qualitative study. Although themes are the primary form of data in qualitative studies, subthemes also provide a plethora of insight and information about participants. Therefore, notes and observations of how participants responded to questions were recorded to provide further support for themes and subthemes of this study.

Data Analysis Process and Procedures

Data collected from the speech-to-text software, field notes, and behavioral observations were used to create coding schema. According to Saldaña (2009), coding is the link between the data collected from participants and how the research provides an explanation which answers the research's purpose. The coding process was done by using the ATLAS.ti software program to code the transcripts and label and organize codes. This program uses four main principles to assist a researcher construct their coding system which includes: visualization, integration, serendipity, and exploration (ATLAS.ti 8 – User Manual). This software does not create the codes, but provides organization for the researcher constructing the coding schema, allowing for categorization, linking, and tracking codes, as well as filtering codes to review and analyze across transcripts. The coding schema therefore represented the themes and subthemes reflected participants' responses that targeted the research questions. Themes and subthemes are created from participants' direct quotes. The themes and subthemes provided evidence to answer the research questions. These themes and subthemes are noted in the results section of this manuscript and their interpretations were noted in the discussion section. They also assisted in understanding any study limitations and what implications the results have for future clinical and research practices.

Validity and Reliability

As previously mentioned in the data collection section, a secure speech-to-text device that does not use audio or video recording was used to collect quotes from participants. According to Leung (2015), qualitative studies produce several types of validity based on the researcher's goal and outcome of the study. These measures consist of first and second tier triangulations (i.e., consisting of researchers verses researchers and theories), multidimensional analysis to establish a case-oriented concept of the study, and respondent verification (Leung, 2015). Peer debriefing was used to provide validity for the coding schema. Peer debriefing is a method used in qualitative researcher to uncover any bias or assumptions within the research study (Janesick, 2015). This process includes meeting with one or more peers who are not a part of the research study and do not present with a bias of the study results.

In qualitative studies, reliability is mostly built on consistency throughout the study (Grossoehme, 2014). Qualitative studies rely mostly on establishing interrater reliability to provide consistency for the created coding schema (Grossoehme, 2014). This process include meeting with a peer who is not involved in the research study and are taught the researcher's coding schema. The peer will then review parts of a transcript and determine if they identified the same coding schema. Following the review of the coding schema between the researcher and interviewer, the codes are tallied to be ran through the SPSS analysis program. Specifically, a Cohen's weighted kappa is the analysis used to compute interrater reliability from the tallied codes (Kvålseth, 1989). The kappa is what determines the consistency of the created coding schema which addresses the research questions.

Reflexibility

In addition, it is imperative for the researcher of a qualitative study to not generalize research attributes for the specific area of interest to prevent research bias (Leung, 2015). This will prevent the research from having analytical generalization, which could lead to a bias of the researcher rather than understanding the findings for what they are. This bias is commonly known as reflexivity, which encompasses personal views of the study and population, and mostly comes from personal backgrounds or understanding of the population under the study.

I received training in both inpatient and outpatient psychiatric settings to provide crisis management for those who live with chronic mental illness. This study was supported with the most recent and relevant evidence based/peer reviewed literature to support the risks and benefits of this study. The supporting literature in this study supports a need for this study to address areas within the research that are lacking. In addition, this research methodology has been designed to help minimize the risk, such as triggering past traumatic memories and causing distress, while still gathering information about participants' experiences particularly with respect to their mental health treatment and services. I have a personal interest in understanding how adults who live with these symptoms perceive the treatment this researcher will be providing as a developing psychologist. I grew up with a mother who lives with mental illness, and I have spent many years processing through trauma and understanding what has and has not worked in my own treatment. Therefore, these experiences have been an influential reason to pursue research in this area and gain awareness of treatment outcomes through a multicultural lens.

Protection of Human Subjects

Once the study was approved to begin data collection, the psychiatric setting and participants were provided documentation which clearly stated any information for their personal records was not be used in this study to protect confidentiality. The information gathered from participants such as any information that may lead to identification of the participant (e.g., name, treatment location) were be kept separate from the participant's responses. Therapists were informed a release of information (ROI) form was required so I could protect the confidentiality of the participant. In addition, to use their support if needed to verify participants' diagnoses. Frequent check-ins were done with the participant after every question to make sure the participant was not overwhelmed and was willing to continue their participation in the study. No participant reported a disinterest or a need to cease their participation and only required short pauses intermittently. No participant reported feeling triggered, distressed, or uncomfortable about sharing their personal histories of trauma and/or experiences. Grounding exercises were used to help alleviate distress as needed. Participants were also reminded they can reach out their providers if need and were informed of the national 24-hour mental health crisis phone line (see Appendix A).

Summary

This study aimed to protect the identities of participants in this study while providing validity and reliability from their lived experiences. In addition, this study aimed to provide potential alternatives to treatment which incorporate multiculturalism through this population’s worldviews. Some potential risks to the participant included: feeling distressed, anxious, or feelings of discomfort from sharing traumatic experiences, or sharing personal information with an unfamiliar individual. Some potential benefits to the participant included feelings of affirmation by sharing their life story and finding comfort in that experience, understanding how individuals who live with mental illness perceive life, and identified areas within behavioral health treatment that would benefit from restructuring.

This population was recruited for this study to gain insight how adults who live with chronic mental illness perceive treatment based on a consumers’ perspective. Although there is ample research on how mental health providers perceive treatment for adults who live with mental illness, this field is lacking strong evidence of how the individual(s) with a mental illness perceives treatment. This research could be used to provide more optimal opportunities for mental health treatment for this vulnerable population. Some potential benefits to the participant include feelings of affirmation by sharing their life story and finding comfort in that experience. By affirming participants’ life stories, participants may feel a greater sense of validation in their life experiences and feel a sense of security that the behavioral health field is striving to increase mental health care. In addition, modifications to treatment should be based on a dual perspective (i.e., the mental health provider's perspective and the patient's perspective). Including both of these perspectives, mental health providers can work closely with patients and tailor their treatment plans to provide optimal care. Hence, an indirect benefit for participants may be knowing that sharing their experiences may ultimately help providers' understanding of how individuals who live with mental illness perceive treatment. That understanding may subsequently lead to providers' improved ability to reinforce trust in a population that often distrusts mental health professionals.

Chapter 3: Results

The purpose of this study was to understand how adults who live with chronic mental illness perceive mental health treatment and their perspectives about the delivery of mental health services. The rationale for this study was to obtain an improved understanding of people's lived experiences to suggest ways to improvements can be made to the mental health system. This study aimed to understand what patients' treatment experience with mental health providers has been like for them and their overall history of treatment. Using a qualitative research method with a phenomenological worldview, five open-ended questions were constructed to obtain knowledge from this vulnerable population. In addition, six demographic questions were used to obtain age, gender, race, marital status, religious/spiritual affiliation, and mental health diagnosis. To have qualified for participation in this study, participants needed to be 18-years or older and have a mental health diagnosis that includes a history of chronic psychosis. Also, participants needed to be stable in their mental health which was determined by participants' mental health providers.

Data Analysis Procedures

A coding schema was developed using software program, ATLAS.ti. The program provides a tool and structure for coding; however, the coding schemas were created by this researcher. The program assisted me to organize coding schema, not create them but provided structure and prevented redundant coding or code co-occurrence (ATLAS.ti 8 User Manual). After fully coding all transcripts in ATLAS.ti, I constructed a total of nine codes, which were used to create themes and subthemes to address the research questions.

An interpretive phenomenological analysis was used to interpret participants' responses to the interview questions. This method is used to support meaning based on one's experiences in life. This analysis assists in developing a greater understanding and significance of study outcomes. For this study, codes were created based on participants' responses to interview questions, followed by peer debriefings and interrater coding to provide validity and reliability for the final coding schema. Peer debriefing provides validity to the themes and subthemes by obtaining an unbiased opinion of the study outcomes to support the strength of the codes created from the data (Richards & Hemphill, 2018). One peer debriefer was used for this study and three transcripts were reviewed to determine if the constructed themes and subthemes were valid representations of the findings. The peer debriefer was a clinical psychology doctoral student who worked as an intern at the psychiatric organization at the time of data collection. The debriefer's experience consisted of working with youth and adults who live with chronic mental illness. Although the debriefer was briefed on the study's research aims, they were not privy to specific measures and procedures used within the coding schema process. The debriefer noted some areas of the coding schema that may have reflected a slight bias based on my experiences of working within inpatient psychiatric care. As such the peer debriefer's comments were taken into account and the coding schema were refined to minimize any potential coding biases.

In addition, interrater coding was used to establish reliability for the study's themes and subthemes. Interrater reliability provides consistency in use of the coding schema to analyze the results (Bardhoshi & Erford, 2017). This process was introduced to a colleague who is not involved in the research study. This colleague is a counseling psychology doctoral student who is familiar with qualitative data analysis procedures. This colleague had the opportunity to review various sections of transcripts that used quotes from participants to create the coding system. The second coder worked in collaboration with this researcher to refine the coding schema, adding three additional codes that emphasized important concepts. The final coding schema was then used to code portions of three transcripts on which a weighted Cohen's kappa through SPSS was computed to establish interrater reliability. The weighted Cohen's kappa was .956 with $p < .001$. This provides high interrater reliability for constructed coding schema.

Participant Characteristics

This section outlines the results that answered the research questions from the previous section. Participant demographics are shown in Table 1 to give context of participants recruited for this study. There were no significant differences in the findings between genders in this study. At the time of this study, all seven participants resided in Washington State.

Table 1

Participant Demographics

Participants	Gender	Age	Race	Marital status	Religion/spiritual practice	Diagnosis
P1	Nonbinary	22	White or Caucasian	Single	Pagan or Nonreligious	F31.0 Bipolar I disorder
P2	Cis-female	52	Hispanic & Caucasian	Single	Christian	F31.0 Bipolar I disorder
P3	Cis-male	44	White or Caucasian	Single	Christian	F20.9 Schizophrenia
P4	Cis-male	22	White or Caucasian	Single	Christian	F20.81 Schizophreniform disorder
P5	Cis-female	39	White or Caucasian	Single	Christian	F31.0 Bipolar I disorder
P6	Cis-female	35	African American & White	Married	Christian	F31.0 Bipolar I disorder
P7	Cis-female	45	White or Caucasian	Married	Christian	F31.2 Bipolar I disorder

Lived Experience of Mental Health Conditions

In this section, themes and subthemes were constructed from the codes used in the research analysis. These themes and subthemes represent lived experiences of adults with chronic mental illness and their backgrounds to understand their perspective of received treatment. In addition, this section articulates recommendations for treatment effectiveness and outcomes of treatment. The goal of the interview questions was to understand positive and negative impacts based on participants' histories of mental health treatment.

Fear

Fear was coded based on participant responses which provided insight to their hesitancy of being actively involved in their own treatment. Most participants reported experiencing varying degrees and types of fear with their treatment experiences which have significantly impacted their ability to seek out care.

Fear of Inpatient Psychiatric Treatment. Their expressed fears were significantly highlighted in their experiences within psychiatric inpatient care. (e.g., "The staff there were so mean and didn't really care and I felt so alone and so scared and begged them to let me see my family" – P7) . According to this participant, a fear of being isolated within an inpatient setting created feelings of fear of their overall treatment. Another participant example from P4 included, "The hospital was so scary! People were violent or screaming a lot and I had a roommate which he cried a lot. I begged my mom to take me out of the hospital and promised I'd take my medications."

Fear of Psychiatric Symptoms. Participants noticeably became more emotional in their expression of inpatient care and frequently required breaks to compose themselves. Not only were participants reporting fear of their own experienced symptoms, but of being isolated from their families as well. P6 stated:

> But there was a 3-day period where I couldn't sleep and just became very paranoid that my husband was mad at our daughter because it was so impactful to me and then I started to see that my daughter was in her crib, but she was dead and covered in blood.

Symptom relief in the hospitals were addressed by medications which had reportedly made participants feel disconnected from themselves and others. This reportedly created a major disconnection and fear of inpatient care for participants.

Confusion

Participants reported experiencing an overwhelming sense of confusion and being disconnected with their treatment while in inpatient psychiatric care. Specifically, participants were confused by their symptoms and whether they could or could not understand the provider at the time of treatment. Participants who have received outpatient care compared to inpatient care reported feeling like they were active in the care compared to be completely detached from it. For example, P6 shared:

> The doctor was overloading me with information when I was clearly manic and or psychotic. Like the education around the diagnosis is important but really? Like I can't understand everything the doctor is telling me when I am still psychotic.

Based on these responses, participants expressed a need for providers to wait until they are experiencing more clarity before providing more in-depth psychoeducation around their diagnoses.

In addition, confusion was also seen in how participants had experienced their symptoms while in the community. P5 expressed:

> I became manic and started to hallucinate that a man was telling me he was going to kill me. I could not tell what was real or not real. I had to speed and swerve on the freeway to get a police officer's attention that I needed help.

Psychosis can be extremely disorienting to the individual, therefore, understanding that the person is in need of help rather than fearing them, can potentially increase greater treatment sustainability. Based on this participant's response, their only option was to use extreme measures to seek help due to the impairment and confusion from their psychosis.

Isolation

Participants expressed feeling completely alone while they were in inpatient care which caused fear and worsening of their symptoms. P7 shared:

> The psych hospitals just wanted to get me medicated and I got stabilized for about 6 months after being at the hospital for 3 weeks. I mean I was still psychotic, and I remember just crying and singing hymns because I was all alone.

In addition, participants reported release of information forms were not properly explained to patients to integrate their families in their treatment, which also made the participant feel isolated and alone. P3 stated:

> When the hospitals show me that form, they just say here sign it so we can talk to your mom about your treatment. But there is a lot of writing, and I don't always understand everything on it which is very confusing, so I just don't sign it and they make me be the bad guy, so I then just stay in my room and feel very alone.

Identity

Most participants reported having a sense of identifying with their diagnosis. Several participants reported feeling de-humanized when they are referred to as their diagnosis (e.g., “When people called me schizophrenic or a druggy when I was younger I hated it, it made me so angry because that’s all I felt like” – P3). By referring to the individual as their diagnosis, this can worsen symptoms by causing the individual to isolate. However, if the participant is taught to separate their diagnosis from their identity, they may experience less symptoms and be less hesitant to seek services. For instance, P5 shared, “. . . which has also helped me to learn that I am someone besides my bipolar, that I have always been told you are bipolar so you have to take these meds for the rest of your life and that has been hurtful at times.” These responses significantly highlight how imperative it is to help people with these diagnoses to separate their diagnosis from their identity as a human being. Also, helping them to see themselves as an individual with lived experiences and that their experiences are unique to them.

Perspectives on Effective Mental Health Treatment

This sections explores specific areas of treatment and experiences with mental healthcare providers as highly effective. These experiences were based on both inpatient and outpatient psychiatric care throughout their history of treatment. The following areas were seen as helpful and had positive impacts on participants.

The first is validation (e.g., “I personally feel that amazing validation from my therapist has been so beneficial” – P1). Validation was seen as a way of being heard by a practitioner and having participants feel their needs are being met. Normalizing concerns around the illness (e.g., “What has worked is having a provider that listens to you, doesn’t make you feel like you are wasting their time, validates you, builds a trust with you, and provides a lot of education” – P5). According to these participants, they felt they are worth a practitioner’s time and that the practitioner is an avid part of the patient’s healing process.

The second is treating the patient like a human (e.g., “Honestly, what has worked is treating me like a human and providing a respectable sense of care. I know I haven’t been easy to work with when I am like that but if people can understand that I cannot control it and that I don’t want to act like that or that I am so scared that I want to be isolated because I don’t want to scare anyone, it is so destructive and heartbreaking; people only see me when I am mentally ill and not when I am mentally well” – P7). This particular area was highlighted as significant in the coding schema. According to participants, being seen as a human being and demonstrating understanding their experienced symptoms is the difference between effective and ineffective care.

The third is being available for questions (e.g., “My psychiatrist would explain the biological things, but the emotional impact was not addressed very well until I met my psychologist, and he does a great job – P2). Although two people may present with same diagnosis, this does not mean their experiences will be the same. As participants indicated, practitioners available to answer questions for their patients provided a sense of being heard and validated by their providers. All of these areas provided great insight has to how these individuals experienced their treatment. In addition, it provides greater insight for what practitioners are doing well in and what can continuously help individuals with chronic mental illness.

Perspectives of Ineffective Mental Health Treatment

This section describes participants' experiences of harmful or ineffective treatment. This includes a lack of treatment involvement from families, lack of psychoeducation provided around a diagnosis, and holding accountability with patients for their treatment. The following themes and subthemes were created to answer the research questions from chapter two of this study.

Psychoeducation

A lack of psychoeducation of diagnoses was another significant area of ineffective care was reflected by participants (e.g., P1 stated, "Things that have definitely been frustrating and not helpful have been when therapists or doctors do not fully explain what the symptoms may consist of and how it will not impact you but those around you"). Providing education around a person's diagnosis is not only imperative for the patient, but equally important for any family system that is involved for support. Chronic mental illnesses present differently with each individual. For example, although two people of the same gender may have schizophrenia, this does not mean their presentation may not be the same. Therefore, it is essential a provider explain these symptoms and relate the symptoms to the individual's experiences, not as it compares to others.

Involving a family member or family system to an adult with chronic mental illness can be the difference between a positive and negative prognosis. As P3 shared, "No mental health provider has even asked me if I would like to have my family involved in my treatment. It's always here is a pill and don't do drugs then they send me home." Involving the family into the support system not only answers the family's questions about their loved one’s diagnosis, but it also helps educate them how to respond and what is good/poor support. P6 expressed:

> Like sometimes I can’t answer his questions so having a mental health professional provide the education around my diagnosis not only to me, but my husband has made such a huge difference. So, if anything from this study, make sure that therapists know to educate their clients’ families too, not just the client.

This inclusion also allows for trust building and healing for any trauma that may have occurred in the family.

Recommended Changes to Mental Health Services

The following themes and subthemes represent participant responses about changes that would be beneficial to improve the delivery of mental health services and how patients receive treatment.

Collaboration

Participants frequently shared their belief about the importance of mental health professionals collaborating with each other and mental health professionals collaborating with the patients’ families. Specific areas where collaboration was highlighted included: who the individual should collaborate with and what that entails, what should the nature of collaboration be like, what makes collaboration successful.

Who the Individual Collaborates With and What That Entails. The first noticeable area of collaboration was seen in a psychiatric provider and behavioral health provider having good communication about their mutual patient’s treatment progress. According to P1, “It is so important that my therapist and psychiatrist talk to each other. It means a lot to me to hear that some mental health providers actually care about having everyone on the same page." Having providers be aware of their patient's treatment progress can help the individual feel like they have a fully supportive team and provide much needed structure. In addition, questions may arise that the other provider is better trained in and, it is appropriate for the provider to defer to the other provider. This is to ensure the patient is getting the best educative answer to their questions. P2 shared, "My psychiatrist would explain the biological things, but the emotional impact was not addressed very well until I met my psychologist, and he does a great job."

The Nature and Success of Collaboration. Another area where collaboration was highlighted was including family members to be involved with the providers. P6 shared, "So, I would say that therapists and psychiatrists should include the families as well which didn't happen for me until I went through the day program at the clinic." Further success is seen when patients with chronic mental illnesses see that their diagnosis does not define every part of their being. Although these diagnoses may be challenging, it is important providers be reminded that their patience is just as need as their patients with their recovery. P5 noted:

> My old ARNP always made me feel like he was trying to get me out of his office as quickly as possible. But now I really like my psychiatrist and my current counselor in the clinic because they communicate with each other and to my mom which has really helped me get through the psychotic episode.

Lastly, success is not only determined by how informed our patients and their families are, but how the general public is informed about adults who live with mental illness. P7 shared, "I think in general people in the public need more education around mental illness. Like I am not a bad person and there is a beauty to bipolar too." As mental health professionals, it is our responsibility to inform the general public about these illnesses and how the community can be more supportive.

Trust

Participants reported a variety of experiences during treatment related to the critical nature of trust. According to the results, adults with chronic mental illness often experience symptoms that impact their sense of trust with others. Also, how providers respond to their patients' needs can grossly impact their sense of trust or mistrust with their provider. Areas that highlighted trust in this study were seen between the provider and patient, and between the patient and a family member or loved one.

Trust Between Provider and Patient. Providers may experience difficulty with trusting their patients at times and yet not inquiring further can impact their patients' health. P7 shared:

> So, after the hospitalizations, I met with a nurse practitioner in the community and had a horrible experience with her! She had me on lithium and my feet began to swell up really bad and I had gotten really dizzy. My husband had called her and said something was wrong, but she said I would be fine until the next appointment. But everything was not fine so we went to the emergency room and the doctor said there was so much fluid from the edema that the fluid could have ended up in my brain and so I immediately stopped the lithium and seeing that nurse practitioner because I did not trust her at all!

As mental health practitioners, it is paramount to hear our patients when they express a concern and respond to it appropriately.

When we begin to hear our patients, they then establish that we trust them to express their need which helps them to be more involved in their treatment. P5 said:

> Yes and that is what I have gotten at least now with my current psychiatrist and my current therapist. I trust them both and feel like they hear me, are honest with me, and answer all of my questions. The lack of education around my diagnoses has been very frustrating and it makes it difficult to feel like you can trust the provider if they won't be honest with you about the symptoms.

Trust Between Patient and Family System. Those who support their loved one with a mental illness often experience mistrust with their loved one to be honest about their health. However, by not giving them an opportunity to try and make mistakes, can cause deeper wounds for the family and for the individual. P1 stated:

> When I was younger I didn't know how severe everything was, so I feel like that interaction with my first two therapists didn't validate how I was truly feeling and hear what I was reporting. It also made my parents not trust me that I was being honest with my symptoms which was hurtful because I was being honest.

Every human has a need to feel trusted and trusting an individual with mental illness can be challenging, but needed to have sustainability. P3 stated, "Which is difficult because I feel like my mom can't trust me at times so I need to know who I can trust. I am glad I have doctors that I can trust."

Summary

This study aimed to understand how adults with chronic mental illness perceive treatment based on their lived experiences and what changes can be made to mental health services. Participants were recruited through a psychiatric organization and asked to participate in an interview to better understand their experiences from their perspectives. This study yielded 10 themes and subthemes from participant responses to the interview questions. The themes and subthemes reflected participants' experiences with treatment and what potential changes can be made to behavioral health treatment. The significance and implications of these results are articulated in the next section.

Chapter 4: Discussion

This study aimed to understand what interventions are and are not working for adults with chronic mental illness. This study also aimed to understand what modifications can made to the field of psychology for this population. This study demonstrates significant importance to understand how treatment and the delivery treatment are being perceived by adults who live with chronic mental illness. This is a marginalized and vulnerable population who often requires a lot of support and attention to their overall health. Overall, this study yielded some imperative insights into how these patients feel treatment is and is not working for them.

The results demonstrated adults who live with chronic mental illness base their perception of treatment on multiple factors including not feeling dehumanized by those around them, trust in their providers and trust with their families, collaboration between providers and between providers and their families (Ahmed et al., 2015), being in a state of confusion due to the experienced symptoms, and the amount of provided psychoeducation around diagnoses. The following section articulates the overall significance of the results section. Following these elaborated explanations, clinical and research impressions are given to strengthen overall treatment, provide future efficacious research studies, and provide a sense of humanity to this extremely marginalized and vulnerable population.

Dehumanizing and De-Identifying a Diagnosis

In reference to the theme “identity” from the results section, the following implications were made. Dehumanizing humans are done both implicitly and explicitly within mental health organizations (Christoff, 2014). Primarily, adults who live with chronic mental illness felt as if they have been identified as not possessing characteristics that are considered normal human behaviors. Dehumanizing a human can have lasting effects that range from mild to severe. According to this study's participants, the effects of dehumanization were seen as having a severe impact on them. Self-identity and awareness of being labeled as a diagnosis have been impactful for this vulnerable population. According to the results outlined in chapter three around identity, participants who were taught to not identify with their diagnosis reported having higher levels of self-esteem and confidence in their personhood. However, this was not reported in all participants of this study, whereas, all participants reported feeling dehumanized and being labeled as their diagnosis. Therefore, as clinicians, it is paramount that psychoeducation needs to include de-identifying the diagnosis as part of the person's human identity.

In addition, identifying with a diagnosis has led to confusion, isolation, frustration, and mistrust between patient and provider. For example, P3 shared, "When people called me schizophrenic or a druggy when I was younger I hated it, it made me so angry because that's all I felt like." In addition, this can lead to anger and feelings of exclusion which has consequences on the overall mental health statuses of patients with chronic mental illness (Geraldo da Silva et al., 2020). Stigma around mental illness can even impact how adults with these chronic conditions handle their illness and how they seek emergency psychiatric care.

Fear of Treatment Providers and Loss of Family

This study provided evidence of participants' sense of fear with providers which impacted their ability to receive effective care. Fear within treatment was largely seen in areas of inpatient psychiatric care. Fear of the physical inpatient environment was analyzed further in Williams et al.'s (2014) study. This study used cognitive behavioral interventions to address fear around the environment and symptomology of adults with schizophrenia. Significant amounts of fear were most prevalent for participants in their interactions with inpatient psychiatric providers and experiencing violence within the hospital units.

This study correlated fear with an inability to see family members or loved ones while in inpatient care and not being competent enough to understand the purpose of the hospitalization. In addition to participants' experiences within inpatient care, the results support a significant amount of fear from experiencing psychotic symptoms (e.g., hallucinations, paranoia) and not being completely aware of their environment. This study's results supported that fear of inpatient hospitalization has been a motivating influence to adhere to treatment. However, this mentality also creates further anxiety due to mistrust in the person's environment. This study did not focus on how interventions can be modified within inpatient psychiatric settings.

Dignity and Self-Determination

The effectiveness of mental health treatment was articulated in three main categories. These categories were common themes based on participants' responses to the interview questions. Although no participants mentioned a specific therapeutic intervention being more effective than others, all participants reported similar positive experiences within their outpatient treatment. All participants reported feeling their treatment has been significantly impactful based on the clinician providing effective validation to the patients' lived experiences. For instance, P1 stated, "I personally feel that amazing validation from my therapist has been so beneficial."

Treatment ineffectiveness was measured by what has not worked well for patients in their treatments, both in an inpatient and outpatient setting. Similar to the previous section, no specific treatment method (i.e., intervention) was mentioned as ineffective. The ineffective qualities of treatment were articulated through participants' experiences in their care and how they felt while receiving care for their illnesses.

Providing Person–Centered Care

Several participants reported experiencing feelings of not being seen as a human with their providers over their history of treatment. According to Rodgers et al. (2018), improved communication between providers and patients are needed to reduce treatment hesitancy. According to P7, "Honestly, what has worked is treating me like a human and providing a respectable sense of care." This implies patients who have chronic mental illnesses and are seeking treatment often feel they are not being considered as a human being, only their diagnosis. This creates hesitancy for pursuing treatment among this vulnerable population.

Being Seen and Heard in Treatment

These results support that patients with chronic mental illnesses such as schizophrenia, schizoaffective disorders, and bipolar disorders have limited experiences of feeling like they are being seen and heard by their providers. Although validation continue to be a relevant strength in the delivery of mental health treatment, patients with these illnesses continue to feel unnoticed by their treatment team.

Feeling Dismissed in Inpatient Psychiatric Care

Although patients with chronic mental illnesses are typically seen at their worst during their hospitalizations, they are still human beings who struggling with an uncontrollable illness. Participants in this study did not distinguish their experiences in inpatient care from a standalone psychiatric hospital or an inpatient psychiatric unit within a medical center. According to P4, “The hospital definitely didn’t help me. It scared me more than anything. I don’t like having to increase medication though because it makes me feel tired and like I can’t do anything.” Overall, participants reported inpatient hospitals were not only negative experiences, but caused or worsened trauma. This could potentially imply further research is needed within inpatient psychiatric facilities to understand how the physical environment of the facility is impacting a person’s overall mental health. Although inpatient units are designed to psychiatrically stabilize patients with psychopharmacological interventions as the primary method of treatment, staff at these facilities may require further behavioral health interventions. For example, P7 stated:

> What has not worked is being dismissive and overloading me with information when I am clearly manic and or psychotic. Like the education around the diagnosis is important but really? Like I can’t understand everything the doctor is telling me when I am still psychotic?

Collaboration Among Mental Health Providers and Families

This study’s findings provided supporting evidence for the need of collaboration among mental health practitioners. According to Wilson et al. (2018), frequent collaboration among professionals are important especially within marginalized populations such as adults with chronic mental illness. Participants in this study providing responses that support current literature's research to encourage providers to work with each other to provide optimal care. In addition, it is imperative to include family members who are able and willing to participate in their loved one's treatment. Although the nature of chronic mental illnesses can be destructive in family systems, it is still imperative to include this system into the support system for the patient (Ahmed et al., 2015).

Provider-to-Provider Collaboration

These results suggest the most optimal mental health care has been delivered to patients when the various providers of the patient's treatment team communicate with each other. According to P5, "Yes and that is what I have gotten at least now with my current psychiatrist and my current therapist. I trust them both and feel like they hear me, are honest with me, and answer all of my questions." Therefore, it is important mental health providers work not only with each other, and work with other medical providers as needed to address the bio/psycho/social/spiritual model of mental health treatment.

Although this option may not always be available depending on the family's willingness to participate and/or the patient authorizing their families to be involved with treatment, it is paramount that practitioners attempt to integrate families with the treatment as frequently as possible. Current literatures share that family incorporation can raise treatment outcomes and require particular delicacy and continuity (Walsh, 2019). Including families not only helps the patient feel supported in their treatment but it also helps the family to stay informed and obtain answers to questions they may have as well. For instance, P6 said, "So I would say that therapists and psychiatrists should include the families as well which didn’t happen for me until I went through the day program at the clinic.” Participants in this study felt significant support when their families were included in their overall treatment.

Psychoeducation

Psychoeducation is one of the most important aspects of a mental health provider’s role (Alizioti & Lyrakos, 2019). This study provided important areas where education is significantly needed within treatment. These areas included: education around a diagnosis, symptoms, what to expect, and answering questions as they arise. According to this study, a lack of psychoeducation caused a sense of frustration for the patient and their loved ones. This frustration includes questions not being answered and participants feeling like they have to do a lot of research to answer their own questions. For example, P1 stated, “Things that have definitely been frustrating and not helpful have been when therapists or doctors do not fully explain what the symptoms may consist of and how it will not impact you but those around you.” Therefore, it is imperative to be prepared to provide psychoeducation as much as possible to assist this vulnerable population.

Psychoeducation Around a Diagnosis

Participants who reported not receiving enough education around their diagnosis felt a significant increase in support after having a provider who offered ample psychoeducation. This includes education around symptoms and how this diagnosis can be limiting or impactful on their support system. According to P2, “When I had a therapist a couple of years before I met my psychologist, I felt like she couldn’t provide enough information about my diagnosis, and I was left with a lot of questions.” It is also important to note that this population requires providers who specialize in the area of chronic mental illness.

Psychoeducation With a Family System

In addition to education being provided directly to the patient, education is needed to for the family system. Often, families come with as many questions if not more and need answers for handling various situations with their loved ones. Participants who had their families regularly participating in their treatment saw longer periods of not being hospitalized and maintaining stability with the support of their family. For example, P6 shared:

> Sometimes I can't answer his questions so having a mental health professional provide the education around my diagnosis not only to me, but my husband has made such a huge difference. So, if anything from this study, make sure that therapists know to educate their clients' families too, not just the client.

This implies further incorporation of education is deeply needed for this population and their families.

Clinical Implications

Implications for policies in mental health treatment may include adhering to the American Psychological Association's policies and using person-centered language (Uhlmann et al., 2015). For example, stating a person with mental illness or who has mental illness as opposed to a mentally ill person (APA, 2020). Person-centered language may potentially help adults with chronic mental illness feel less marginalized by separating their identities from their diagnosis. This may ideally create more self-esteem and a desire to seek support as needed. Other policy adaptations could be seen in collaborating with psychiatric providers (i.e., psychiatrists or psychiatric nurse practitioners) to integrate this language with their patients. It is imperative to understand how a patient wants to addressed and what they are needed from their treatment, to feel as if they have a voice in their treatment.

The following implications are being suggested based on participant responses. The first implication consists of providers being trained and having experience to work with this population (i.e., following APA ethic code 2.01 boundaries of competence). This population is considered particularly vulnerable and therefore, clinicians who are trained and experienced with this population should take a lead of this population's treatment. This population may also present with various psychological challenges and often requires the clinician to have a basic understanding of medications used to treat these disorders. Although medications are the primary source of treatment for this population, therapeutic interventions can be used to reinforce healing and success (Steinert et al., 2017).

The second implication is using person centered language with a diagnosis. Person centered language reinforces the person's identity as a person, not as their diagnosis. This reinforces an understanding that this vulnerable population are still human beings and therefore deserve to be treated like humans (Applegate et al., 2013). Practitioners can help destigmatize this populations' diagnoses by conversing with their patients and understand how the patient wants to be addressed as to avoid feelings of discomfort. According to Christoff (2014), dehumanizing and stigmatization is done both implicitly and explicitly within mental health facilities. Examples include referring to the patient as their diagnosis and not encouraging the patient to separate their identity as a person from their diagnosis. Other examples including educating others in the general community to not refer to adults with mental illnesses by their diagnoses to prevent stigmatization.

Other practices include clinicians providing a more in-depth education around their patients' symptoms and diagnoses. This education includes answering questions with honesty and not assuming a patient cannot handle the answer. According to participants from this study, this has made them feel frustrated and like there is difficulty with trust between them and their provider. For example, P7 stated, "Also, I think there is not enough education about the diagnosis given to the person who is struggling which is so frustrating to me and makes it hard for me to trust my doctors when I am unstable." However, clinicians should consider moving away from using clinical terms (e.g., hallucinations, mania, or suicidal thoughts) and replacing these clinical questions with more relatable experiences. For instances, a clinician suspects their patient may be hallucinating, present your question as such:

> Do you hear a voice that you are not sure if they are around you or not? Do you feel as if everyone is telling you that what you are saying is not real? Can you see something that others say they cannot see it?

These questions may potentially remove the clinical terminology and make these questions feel more relatable to the patients' experiences.

Education is not only important for the patient, but it is also important in offering education to a support system that is able and willing to have others involved in. For example, "My family has been heavily impacted by my bipolar and our family has pleaded with doctors to be more upfront and include specifics with my diagnosis so they can understand the diagnosis better.” Although education not only provides structure for the patient, it can provide structure for those supporting a loved one with a chronic mental illness. This also includes being patient with your patients who are struggling and may require you to repeat already taught concepts. As clinicians, we can provide more informative education for our patients, their support systems, and to the general public.

All of these aspects may develop a more compassionate environment for those who are struggling with chronic mental illness. As such, it is our responsibility to provide a sense of humanity and education to those whom we treat. In conclusion, the general public’s understanding of this type of illnesses are significantly skewed as evidenced by the results of this study, and more education around mental illness in the general public is significantly needed. Areas where this information can be disseminated at include outpatient psychiatric clinics, community mental health clinics, medical clinics, medical centers, inpatient psychiatric hospitals, correctional facilities, and in colleges or universities.

Study Limitations and Future Directions

This study placed great emphasis on understanding treatment effectiveness and what changes can be made to the delivery of treatment. Limitations to this study included a lack of diversity in diagnoses and a smaller number of participants in the study. A lack various diagnostic presentations may potentially provide different perceptions based on lived experiences. For instance, illnesses such as schizophrenia can be more limiting to an individual compared to an individual with a bipolar disorder. A larger number of participants with chronic mental illness may have potentially provided additional perspectives to understand treatment perception and what changes can be made.

These results were based on participants' perceptions of current and past outpatient psychiatric experiences. However, a significant number of participants reported having negative experiences while in inpatient psychiatric care. Further quantitative and qualitative research studies in inpatient psychiatric setting can provide a diverse perception of how patients receive treatment and how physicians and psychologists can collaborate more effectively to help people heal. Quantitative studies could measure statistical significances of how patients with chronic mental illnesses respond when providers use person-centered language. For instance, running a statistical analysis on impact on a person's identity when a person is addressed as their diagnosis (i.e., the independent variable is person-centered language, and the dependent variable is identifying with a sense of self). Although qualitative studies could further research how a lack of person-centered language impacts to the person's overall sense of self as they relate to their mental illness.

Potential research implications may include measuring treatment effectiveness in inpatient psychiatric settings, identity of self and others as it relates to diagnoses, and treatment outcomes from having family included with treatment. According to collective participant responses, inpatient psychiatric care was not considered as a helpful intervention with their mental illness. For example, P5 said, "The ARNPs in the psych hospitals were horrible! They never really sat there and listened to me or answered my questions." Therefore, comparative studies could produce more helpful treatment outcomes in inpatient care. As previously mentioned, further research can be conducted to understand how a person with chronic mental illness identifies with their sense of self and their mental illness. Future studies can also include the impact a family has for caring for a loved one with mental illness. As indicated by these participants, families are requiring as much attention and care as the person who is living with the mental illness.

Qualitative studies can be conducted to better understand what a family of someone with mental illness needs to provide helpful and healthy support. Additional potential studies may include understanding the perceptions of a support system for a person with mental illness overall treatment. For example, if a person within the support system has questions about the treatment, then the questions can also be answered with appropriate permission given by patient. Also how families perceive their loved ones' treatment based on the amount of education is provided to families that are able and willing to participate in their loved ones' treatment (e.g. "My therapist has been really involved with my mom about my treatment which has been helpful because I forget" – P4). This research could potentially provide ways of strengthen support for those who live with chronic mental illness.

Conclusion

This study was comprised of seven participants to gain insight into how they perceive mental health treatment and what changes could be made within behavioral health. In addition, this study objective was to understand life and lived experiences of adults with chronic mental illness. This study reflects significance by obtaining perceptions of treatment directly from patients who live with these mental illnesses. According to participants, several areas were identified as being significant in how they felt treatment was effective or ineffective. Several areas of treatment strengths and challenges were identified in this study. Overall strengths in treatment included providing validation, clear and frequent communication, and collaboration among providers and their patients' loved ones. Areas requiring further strengthening include validating this population as human beings, destigmatizing mental illness, helping patients to separate their identities from their diagnosis, and providing more in-depth psychoeducation to the patients and their families.

Appendix A

Informed Consent Form

You are invited to participate in a research study conducted by Chance Gallo, a doctoral student at the College of Social and Behavioral Sciences of Northwest University. The purpose of this study is to understand how adults who live with mental health challenges and traumatic life experiences perceive treatment. In addition, this study aims to understand what modifications may be made to the delivery of mental health services.

To qualify for participation in this study, you must be an adult age 18 or older. Participation in this study is completely voluntary and you may stop participation for any reason, at any time and your information will not be used in this study. In addition, there will not be any negative punishments if you decide to no longer participate or refuse to participate. If you agree to participate in this study, you will be asked to engage in an interview for approximately 60 to 90 minutes. Demographic questions will be asked first to gain basic information about you (i.e., race, gender, age, etc.). Questions during the interview will consist of understanding you as a person and your life experiences, the opportunity to discuss past or current traumatic experiences in your life, and what you feel has or has not worked for you in your history of treatment.

There are minimal risks to participating in this study; however, it is possible you may feel some discomfort such as anxiety or uncomfortability by sharing about your history and/or some of your life challenges. The goal of this research is to provide a safe place for you to share about your life and to further understand of how mental health professionals can provide effective care. If you feel distressed at any time by sharing about your life experiences, appropriate resources will be provided to you. Resources include a 24-hour mental health crisis hotline number (1-800-273-8255) and your outpatient providers. One benefit of participating in this study is for you to be given the opportunity to share your life experience and offer insight about the mental health services you have received.

If you consent to participate in this study, your answers to interview questions will be used in this research for publication at Northwest University and may be used for publication in future scientific and/or academic journals. The interviews will be audio recorded through a "speech-to-text" secure device that will be used without recording your voice to maintain confidentiality. Your name, medical record number, or other personal identifications will not be used in this study. Keeping your identities confidential is a top priority in this study and you will be given a letter and number to identify your information rather than your name. There are limits to this confidentiality, such as you making statements that you may be a danger to yourself or others. If such statements are made during this research study, confidentiality will be broken, and the appropriate resources will be notified to maintain your safety and the safety of others. The results of this study will be used for the doctoral dissertation requirements of the Doctor of Psychology (PsyD) program at Northwest University, publication and/or conference dissemination, and potential publication of academic or scientific journals.

The audio recordings will be permanently deleted on January 1, 2022. However, this researcher would like to keep the digital transcripts that do not identify anyone by name in perpetuity.

If you have any questions following this study, please feel free to contact me at xxxxx@northwestu.edu. If you have further questions, please contact my faculty advisor Dr. Leihua Edstrom at Leihua.edstrom@northwestu.edu or (425) 889-5367. You may also contact the Chair of the Northwest University IRB, Dr. Cherri Seese, at cherri.seese@northwestu.edu or (425) 285-2413. Thank you very much for your consideration in participating in this study.

By signing below, I consent that I have the mental and emotional capacity and legal authority to sign this consent form.

Participant Printed Name: ________________________________

Participant Signature: ______________________________ Date: ________________

Chance Gallo, M.A., LMHC-A
Doctoral Student
Northwest University
xxxxx@northwestu.edu

Researcher signature: ______________________________ Date: ________________

Leihua Edstrom, Ph.D., ABSNP
Dissertation Chair & Advisor
Northwest University
leihua.edstrom@northwestu.edu

Advisor signature: __________________________________ Date: ________________

Appendix B

Demographic Questions

1. What is your age?
2. How do you identify your race?
    - White/Caucasian
    - Black/African American
    - Hispanic/Latino
    - Asian
    - Pacific Islander
    - Native American
    - Other:
3. How do you identify your gender?
    - Cisgender male
    - Cisgender female
    - Transgender male
    - Transgender female
    - Nonbinary
    - Prefer not to answer
4. What is your marital status?
5. What is your religious/spiritual affiliation?
6. What diagnosis(es) have you been given by a mental health provider (e.g., psychiatrist, psychologist)?

Appendix C

Interview Questions

1. Tell me a little bit about what your childhood was like growing up.
2. What event(s) of your childhood do you recall having a big impact on your life? These can be good or challenging/hard experiences.
3. What mental health services have you received throughout your life?
4. What has been your experience in receiving mental health services in the community?
5. What do you feel has worked and/or not worked for you in your treatment in the community?

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