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A Mixed-Methods Exploration of Quality of Life in Forensic Inpatients with Schizophrenia Spectrum Disorders on the Social Learning Program

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A MIXED-METHODS EXPLORATION OF QUALITY OF LIFE IN FORENSIC INPATIENTS WITH SCHIZOPHRENIA SPECTRUM DISORDERS ON THE SOCIAL LEARNING PROGRAM

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In partial fulfillment for the degree of
DOCTOR OF PSYCHOLOGY

by

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A MIXED-METHODS EXPLORATION OF QUALITY OF LIFE IN FORENSIC INPATIENTS WITH SCHIZOPHRENIA SPECTRUM DISORDERS ON THE SOCIAL LEARNING PROGRAM

This dissertation, by Alexa Hutzenbiler, has
been approved by the committee members signed below
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DOCTOR OF PSYCHOLOGY

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ABSTRACT

A MIXED-METHODS EXPLORATION OF QUALITY OF LIFE IN FORENSIC INPATIENTS WITH SCHIZOPHRENIA SPECTRUM DISORDERS ON THE SOCIAL LEARNING PROGRAM

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This mixed-methods study explored the quality of life and lived experiences of adult individuals with diagnoses of schizophrenia spectrum disorders residing and receiving treatment on the Social Learning Program (SLP) at Fulton State Hospital, a high-security state forensic facility. Eleven participants completed the WHOQOL-BREF quantitative quality-of-life measure. Ten participants completed in-depth, semi-structured, qualitative interviews. Interviews were transcribed then analysed using Interpretive Phenomenological Analysis. The major themes that emerged included “Working the Program,” “Relationship Dynamics with Self and Others,” “Meaning,” “I’ve Been Having Breakthroughs,” and “Areas for Improvement in the Program.” Combined, the findings of the present investigation demonstrate the utility of the SLP and highlight the importance of studying the lived experience and quality of life of individuals with diagnoses of schizophrenia spectrum disorders residing in forensic facilities. This dissertation is available in open access at AURA (https://aura.antioch.edu) and OhioLINK ETD Center (https://etd.ohiolink.edu).

Keywords: Social Learning Program, serious mental illness, forensic psychiatry, quality of life, interpretative phenomenological analysis

Dedication

To all those with lived experience of serious mental illness and to those who love them. May we continue to find ways to promote recovery, growth, compassion, and understanding.

Acknowledgments

Thank you to anyone and everyone who has supported me throughout this journey. I would like to especially express my gratitude to my dissertation committee, Dr. Toohey, Dr. Kennedy, and Dr. Pardee, for their support, compassion, and guidance. Thank you to my parents and grandparents, who provided the foundational values of hard work, integrity, and passion, and made higher education more accessible to me. To my siblings, for thinking they can dance. To my husband Robbie, thank you for always supporting me through all the chaos and navigating our lives thousands of miles apart (and being the best dog dad to Phoebe). To my closest friends, near and far, and to my in-laws, thank you for always being my biggest fans. Thank you to Dr. Gregory Zarow for his patience and assistance with statistical analysis and editing. Lastly, thank you to the people who participated in my study and offered their vulnerability and lived experiences.

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CHAPTER I: INTRODUCTION

Overview

Many individuals with serious mental illness (SMI) face significant obstacles in their journeys toward recovery, including numerous that directly impact their quality of life (QoL). These obstacles are compounded if these individuals find themselves needing involuntary psychiatric care, and even more so if the care is in a forensic setting or system. This dissertation explored the intersections of The Social Learning Program (SLP), QoL, lived experiences, and forensic psychiatry. This dissertation examined how inpatient, forensic, psychiatric clients who reside and participate in treatment on the SLP describe the quality of their lives, their lived experiences, and how they have made sense of these experiences as it relates to their current treatment.

The clinical implications of this dissertation are to offer insights to frontline staff and other clinicians who offer every day care, professionals looking to make changes within this system, and administrators looking to provide cost-effective care that is also efficacious for clients. Further, this dissertation can help inform the development and implementation of future research and possible intervention by highlighting specific issues and strengths relevant to this population.

Research Question

The research question for this study was, “What is the quality of life (QoL) for individuals residing in a forensic hospital with diagnoses of schizophrenia spectrum disorders who participate in the Social Learning Program (SLP)?”

Purposes and Goals of the Dissertation

This dissertation centered on exploring QoL, lived experiences, and meaning making of these experiences in individuals with serious mental illness (SMI) participating in the Social Learning Program (SLP) in a maximum-security forensic hospital, Fulton State Hospital. A discussion of these factors offers insights to a variety of individuals, including nursing staff who provide day-to-day care and support, clinicians responsible for interventions and treatment planning, and administrators who participate in the allocation of funds for care, which includes the implementation of treatment. Further, implications of this dissertation inform the development and implementation of future research and possible intervention by highlighting specific issues and strengths relevant to this population.

This dissertation used both qualitative and quantitative approaches, in a convergent parallel mixed methods design. This design suggests the researcher simultaneously collects both sets of data, later integrates the findings, and explains the areas of convergence and divergence (DeCuir-Gunby & Schutz, 2017). Using a mixed methods approach with this population allowed for greater levels of inclusion and ensured that the maximum number of voices were heard. Although a qualitative project would likely have been sufficient in garnering responses, negative symptoms of SMI diagnoses can lead to lasting thought impoverishment, response latency, and difficulty articulating oneself (Krynicki et al., 2018). Thus, the need for a quantitative component with responses captured by a survey with Likert-based responses.

Quantitative data was collected using a standardized survey instrument for measuring QoL, the WHOQOL-BREF, which is a brief, 26-item self-report measure, especially useful for measuring outcomes with adults with psychosocial disability (Hawthorne et al., 2006; Shawver et al., 2016).

To provide a thorough investigation and in-depth study of this population, this dissertation used Interpretive Phenomenological Analysis (IPA) from hermeneutic phenomenological philosophy. An overarching IPA framework allowed participants the opportunity to describe their experiences, triumphs, and challenges as they have navigated the SLP. IPA gave participants the opportunity to discuss the impact this program has had on their perceived QoL and how they have made meaning out of this experience.

It is important to note some of the complexities of conducting mixed-methods research. First, the two types of research require different methods of establishing validity/trustworthiness and reliability/credibility; in the methodology chapter, I discussed the steps I took to increase these. Second, a mixed-methods approach takes significantly more time and resources than completing just a qualitative or quantitative project; this is particularly true because of the Interpretive Phenomenological Analysis (IPA) framework that requires a comprehensive transcription, coding, and analysis process. Lastly, utilizing this type of methodology may provide unbalanced sample sizes, with quantitative research typically including a higher N than qualitative research; I addressed this further in the limitations section of the Discussion chapter.

Limitations of Previous Research

The majority of the previous research that has focused on QoL with this population (individuals with SMI who are receiving inpatient psychiatric care, whether civilly or through a forensic process) has been conducted outside of the United States, particularly in the last 15 years. Additionally, there is currently no research that has investigated the QoL of individuals participating in the Social Learning Program (SLP); to this writer's knowledge, no qualitative research has yet been conducted to explore lived experiences of the SLP participants. Considering these factors, the current literature lacks an understanding of what this experience is like, how participants describe their QoL, as measured by the WHOQOL-BREF, and how they make sense of their experiences and how these experiences individually and collectively impact their QoL. Additionally, despite consistent empirical research on the SLP and its successes in inpatient populations, the current literature lacks an understanding of how the SLP impacts QoL in its clients, and therefore fails to clarify if the SLP surpasses other inpatient treatment programs in this domain. By evaluating QoL and investigating the lived experiences, results can complement the SLP's empirically sound foundation by offering a subjective perspective into the client's experience. Thus, this dissertation sought to bridge the gap in research, and additionally, to examine what has been most enjoyable and what has been most challenging about participants' experiences. Lastly, this dissertation sought to address the lack of research investigating (a) the lived experiences of individuals receiving inpatient psychiatric care on a forensic basis, (b) QoL of this population within a specific treatment context, and (c) research with this population in the United States.

Therefore, the current dissertation outlined the literature gaps that indicated necessity of exploring these experiences and garnering information about QoL. This first chapter provides an overview and justification for the current project. It also includes brief descriptions of terms of various important constructs. The second chapter, the literature review, first explores the definition and history of serious mental illness (SMI), as this serves as a foundational concept for this dissertation. The literature review then investigates the rationale for and history of the Social Learning Program (SLP). Additionally, the literature review describes how QoL was constructed, operationalized, and used in a variety of contexts and cultures, with specific detail about how it has been applied to individuals with SMI, as well as in forensic inpatient settings. Lastly, information about qualitative research, namely interpretative phenomenological analysis (IPA, is included. This section includes a review of studies that have utilized IPA for investigating the lived experiences and meaning making of individuals with SMI, as well as demonstrations of research geared toward understanding QoL in a variety of populations. The third chapter outlines the research question and the subsequent methodology used to answer this question, as well as specific descriptions of the mixed-methods approach for the current dissertation. The fourth and fifth chapters describe the results and discussion, respectively.

Definition of Terms

The following concepts are briefly described here and more thoroughly investigated in the subsequent literature review chapter.

Serious Mental Illness

Assisting individuals with lived experience of serious mental illness (SMI) has been a focus of various global communities for hundreds of years (Paul & Lentz, 1977). Historically, asylums and institutions were created as a means of housing these individuals and providing various “treatments,” often driven by religious beliefs that a person’s mental illness was caused by demons or undesirable personal characteristics. There have been many reforms surrounding the treatment of those with mental illness, and in more recent years, most mental health hospitals are geared toward recovery and reintegration into the community of people with lived experience of SMI. In the United States, the intersection of mental illness and the criminal legal system has received increasing attention and concern (Prosono, 2017; Wik et al., 2020). Forensic psychiatric hospitals have been created and fulfill a need in the community to aid individuals who are court-ordered for a variety of inpatient mental health services, including individuals who have been deemed incompetent to stand trial, not guilty by reason of insanity or by mental disease or defect, or guilty but mentally ill (Menditto et al., 2015). While these concepts will be discussed in more detail in the literature review, they all have directly impacted the care, QoL, and reintegration into the community of those with SMI.

Overall, the population included in this dissertation has one core commonality: impairment related to a serious mental illness (SMI), which typically includes diagnoses of schizophrenia, schizoaffective disorder, and other affective disorders such as those on the bipolar spectrum or severe major depressive disorder (Ruggeri et al., 2000). Ruggeri and colleagues (2000) suggested a two-dimensional approach that will be discussed in more depth in the literature review section. The current dissertation will use Ruggeri and colleagues' conceptualization of serious mental illness*,* with focus on the mental illness' duration and impact on a person's life, rather than the narrowed approach of including only those with a psychotic process (Ruggeri et al., 2000). Practically, admission criteria for the Social Learning Program (SLP) at Fulton State Hospital (FSH) uses a similar framework, focusing on the presence of persistent mental illness, current hospitalization of one year or more and/or failed reintegration attempts into the community, high rates of bizarre behavior, and noted deficits in one or more areas of adaptive functioning, including social skills or maintenance of hygiene or grooming.

The Social Learning Program

The Social Learning Program (SLP) is a highly esteemed form of psychosocial rehabilitative programming in psychiatric facilities that house, teach, rehabilitate, and reintegrate individuals with serious mental illness (SMI; Paul & Lentz, 1977). The underlying premise of the SLP is that anyone, regardless of psychological functioning, can learn new skills and modify behavior in positive ways (Menditto, 2002). The SLP has been recognized by the American Psychological Association's (2007) Task Force on Serious Mental Illness and Severe Emotional Disturbance as a best practice for inpatient treatment. There are numerous studies indicating its efficacy and utility, (Newbill et al., 2011), such as reducing instances of aggression while residing on inpatient wards, decreasing bizarre and/or inappropriate behavior (Paul & Menditto, 1992), and lowering rates of rehospitalization after discharge to the community (Goodness & Renfro, 2002; Menditto et al., 2022; Paul & Lentz, 1977). Additionally, results demonstrate measurable increases in social skills and treatment adherence (Bellus et al., 2003; Curran et al., 1991; Silverstein et al., 2006) in civil and forensic populations alike (Beck et al., 1991; Newbill et al., 2011). Specific details about the context and zeitgeist of the time before and during the emergence of the SLP will be comprehensively discussed in the literature review, as will research findings that have been presented in the last 35 years.

Quality of Life (QoL)

The term *quality of life* has been used over the last 100 years to describe a multitude of aspects related to a person's overall functioning and satisfaction with life (Wood-Dauphinee, 1999). There has been debate on a definitional operation and whether subjective and/or objective information should be included in evaluating QoL (Campbell, 1981; Corring, 2002; Eack & Newhill, 2007; Kerce, 1992; Lehman, 1988; Ruggeri et al., 2001). However, researchers can generally agree QoL encompasses facets of psychological, social, and physical health, as well as relationships, life satisfaction, and perceptions about one's well-being (Wood-Dauphinee, 1999). Recent literature has indicated newfound interest in studying QoL of participants in a variety of contexts, cultures, and languages, including QoL in individuals with serious mental illness (SMI; Dong et al., 2019; Eack & Newhill, 2007; van de Willige et al., 2005) , as well as individuals who reside and receive care and treatment in forensic inpatient psychiatric settings (Büsselman et al., 2021; Schel et al., 2015; van Nieuwenhuizen & Nijman, 2009; Vorstenbosch & Castellitti, 2020; Vorstenbosch et al., 2014).

CHAPTER II: REVIEW OF RELEVANT LITERATURE

Mental Illness: The History

The history of identification, diagnosis, and treatment of mental illness dates back hundreds of years. While mental illness itself has likely existed since the emergence of humankind, places to house, and eventually to treat, rehabilitate, and reintegrate individuals with lived experience of mental illness were introduced as early as the thirteenth century. Shorter (1997) suggested asylums have existed since the Middle Ages, as Western societies have always looked for ways to separate the mentally well and unwell. Traditionally, asylums served a custodial function only, to keep individuals with mental illness away from society, as there were no medications or other effective treatments for illnesses, nor was there belief that people with mental illness could participate satisfactorily in society and lead meaningful lives.

One of the first formal psychiatric hospitals to be built was Bethlem, in the United Kingdom, or “Bedlam” as it came to be nicknamed, a result of its reputation as a cacophonous, unruly, dangerous asylum. Bethlem was described in history books as early as 1329. By 1403, the hospital housed six men who were determined to be “insane” (Shorter, 1997, p. 4). Though the infamous conceptualization of asylums did not come to fruition until the mid-to-late eighteenth century, psychiatric hospitals existed throughout this time and could house anywhere from a few clients to hundreds. Private psychiatric hospitals existed for families that could afford them, while it seems many individuals with lower socioeconomic status received care in jails or public psychiatric hospitals, which were often significantly overcrowded and poorly staffed. It was these public hospitals that slowly transformed into the custodial institutions that would later be referred to as asylums (Morrissey & Goldman, 1986). These changes occurred as the world saw the emergence of industrialization, increased homelessness (Morrissey & Goldman, 1986), two World Wars, and staggering ballooning in numbers of psychiatric inpatients (Grob, 1995). As this happened, the field of psychiatry declined “from rehabilitation to custodianship” due to the extreme overcrowding and lack of providers (Rothman, 1990, as cited in Shorter, 1997, p. 46).

Beginning in the early 1960s, there was a heightened emphasis in the United States to deinstitutionalize individuals with mental illnesses by releasing them from asylums and encouraging outpatient community support (Martínez-Martínez et al., 2020). Though deinstitutionalization did not officially come to fruition until President Kennedy signed the Community Mental Health Act into action, the era came after several decades of significant public opposition to the asylums as they had been existing. Once the Community Mental Health Act was signed by President Kennedy, individuals living in asylums began their rapid, forced exits into the community (Grob, 1995). In November 1963, within one month of the enactment of the Act, Kennedy was assassinated.

The next 30 years included the United States entering into the Vietnam War and various presidencies that either prioritized or ignored mental health and subsequent funding for these necessities, all of which resulted in widespread fractures in community mental health (Grob, 1997); those with the most serious and chronic impairments quickly became the most seriously disadvantaged (Morrissey & Goldman, 1986). This has caused extensive and pervasive problems to the mental health system, which in turn, have caused a multitude of issues for other systems which converge with this one, primarily the criminal justice system. In the United States, there are approximately two million jail bookings of persons with a diagnosed serious mental illness (Steadman et al., 2009), two in five people who are incarcerated have a history of a diagnosed behavioral health disorder (United States Department of Justice, 2017), and nearly one in four people who were shot and killed by police between 2015 and April 2022 had a diagnosed mental illness (Tate et al., 2022).

Additionally, forensic psychiatry and psychology have become increasingly prevalent in the last 50 years, with dramatic increases in admissions to forensic psychiatric wards and hospitals throughout the United States since the late 1990s (Prosono, 2017), and a 76% increase in number of forensic patients residing in a state psychiatric hospital between 1999 and 2014 (Wik et al., 2020). These hospitals are designed to admit individuals who are involved in the criminal justice system due to an alleged offense when there has been a mental health-related question(s) posed by the court. Though the specific descriptions of forensic terms may vary slightly by state and jurisdiction, these questions are typically related to the person's competency (i.e., ability to understand and assist their defense attorney in court proceedings) and culpability (i.e., whether they were sane at the *time* they allegedly committed the offense; *not guilty by reason of insanity*). Other reasons a person may be admitted to a forensic psychiatric facility could be related to a court ruling of *guilty but mentally ill (GBMI)* or if a person has been determined to be a sexually dangerous person with a mental illness (language varies by state; Wik et al., 2020).

While identification, diagnosis, and treatment of mental illness has existed since the earliest asylums, there have been many twists and turns arrive at the present-day state of the mental healthcare system. This current system now intersects with a variety of comprehensive institutions and systems, including community mental health and facilities for clients with treatment and forensic needs.

Serious Mental Illness: The Term

The term *serious mental illness (*SMI; also known as *severe mental illness* and *severe and persistent mental illness*) emerged in the second half of the 20th century (Goldman et al., 1981). As mentioned, the 1950s and 1960s were a time of increased advocacy for individuals with mental illness in hopes that the deinstitutionalization movement would have them discharged from asylums and reintegrated into society (Grob, 1995). As such, there was also interest within the field of psychology to remove stigmatizing terms for the mentally ill, such as the term *chronically mentally ill* (Goldman & Grob, 2006). Terms such as this were described as "having negative connotations" and implying there was no hope for their future or for recovery (Goldman & Grob, 2006, p. 742). Since then, the operational definition of SMI has been ambiguous, lacked clarity (Martínez-Martínez et al., 2020), and lacked consistency in its usage (Ruggeri et al., 2000). While the purpose of this dissertation is not to address the inconsistencies of the definition of SMI, it is important to note because even with the extensive research on SMI, the operational definitions have greatly differed depending on the study and its authors.

Heterogeneity in the diagnoses included under the umbrella term of SMI has been described in a meta-analysis of existing SMI research (Martínez-Martínez et al., 2020), as well as other extant research (Berghöfer et al., 2020; Ruggeri et al., 2000). In other studies, including several that specifically examined effects of the SLP on clients with SMI (Menditto, 2002; Menditto et al., 2022; Oehler et al., 2018; Paul & Menditto, 1992), the term SMI is used without reference to specific diagnoses. As a result, there is no single diagnosis or group of diagnoses included in the broad category of SMI; however, typical diagnoses include schizophrenia, schizoaffective disorder, and other affective disorders such as those on the bipolar spectrum or severe major depressive disorder (Ruggeri et al., 2000). Ruggeri and colleagues (2000) suggested a two-dimensional approach to defining SMI as inclusive of any mental disorder, excluding personality disorders, that (a) has a duration of two or more years and (b) causes mild to severe dysfunction as indicated by the Global Assessment of Functioning (GAF) scale (scores of 70 to 50 or lower, respectively). This conceptualization of SMI posited by Ruggeri et al. (2000) was primarily based on the National Institute of Mental Health's 1987 definition; this conceptualization is the premise of the definition of SMI for this dissertation as well.

The Social Learning Program

This section examines the factors that led to the creation of and need for the Social Learning Program (SLP), the pilot study conducted by Paul and Lentz (1977) that examined the effectiveness of the SLP, and the subsequent history of the SLP's success in inpatient settings. First, to grasp why new inpatient treatment approaches were being considered, it is important to examine the unintended consequences of inpatient psychiatry was causing in the patients it was treating: namely, a phenomenon titled *social breakdown syndrome.*

Social Breakdown Syndrome

As previously discussed, long-term psychiatric facilities are infamous for their role in the treatment of people with mental illnesses (Eghigian, 2019). Beginning in the late 1940s and early 1950s as psychotropic medications were being introduced, clinicians and researchers began investigating the causes of mental illness and the reasons why interventions were ineffective (Gruenberg, 1974; Gruenberg et al., 1966; Paul & Lentz, 1977; Zusman, 1966). Despite a common belief that individuals with serious mental illness, namely schizophrenia, simply declined in functioning throughout the lifespan due to age (i.e., a natural aging process), newer research indicated prolonged hospitalization was, in fact, typically the culprit of significant decreases in functioning (Honigfeld & Gillis, 1967). The interaction between clients and their environment was investigated (Mariotto & Paul, 1975; Zusman, 1966), and the concept of *social breakdown syndrome* arose from this research (Zusman, 1966). The term is described as "a wide range of overt disturbed behavior" (Gruenberg, 1974, p. 20), which could include neglecting one's hygiene needs, dangerous behavior to self or others, and withdrawal.

Despite the creation of the 1963 Community Mental Health Centers Act and the rapid decline of long-term institutionalization, individuals with serious mental illness continued to struggle in the community. This resulted in a dramatic uptick in readmissions of the same clients (Paul & Lentz, 1977). Gruenberg (1974), one of the leading researchers on social breakdown syndrome of the time, described events that could cause the onset of social breakdown syndrome of a person with mental illness in the community, including labeling, rejection, and stress. Institutionalization further exacerbated social breakdown syndrome because of isolation, identification as a patient, and high levels of expected compliance (Gruenberg, 1974). At this point in history, it seems that clients were crowded into locked psychiatric hospitals, had minimal treatment programming or therapeutic interactions, and had their freedoms and personal items taken away. Clients seemed to be responding with increased psychiatric decompensation and frequently dangerous behavior because of the combination of their mental illness and the confined, dull environment (Zusman, 1966).

Additionally, traditional inpatient psychiatry emphasized the importance of cleanliness, timely paperwork completion, and on-time medication administration, leaving minimal time for staff to interact with clients (Paul & Lentz, 1977). Furthermore, extended admissions also led to lost opportunities for clients to practice the skills necessary for successful community living; oftentimes in psychiatric hospitals, clients are responsible only for keeping their own bodies clean or changing clothes. Other tasks of daily living are typically done for them by staff; meals are cooked and served, laundry is completed, and living areas are cleaned. The longer amount of time a person spends in an institutional setting, the longer they go without practicing these skills, making reintegration into the community as an independent person incredibly difficult. As such, even when clients did discharge, many struggled to remain in the community due to subsequent decompensation, noticeable social deficits, and difficulty caring for themselves (Glynn & Mueser, 1986). Additionally, clients who had admissions for two years or longer had only a 6% chance of discharge and continued success in the community (Paul & Lentz, 1977).

Because of the primarily custodial function of psychiatric hospitals at the time, limited therapeutic interventions were taking place (Morrissey & Goldman, 1986). The few therapeutic approaches that existed at the time had limited empirical data to support them (Paul & Lentz, 1977). Due in part to these reasons, Paul and Lentz examined two emerging therapy approaches, one titled the milieu therapy approach, and the other labeled as the social learning approach. The two approaches "focused upon resocialization and the reduction of extreme bizarre behavior… [and] emphasized a psychosocial focus" (Paul & Lentz, 1977, p. 7). The two approaches had shown promise but lacked the empirical evidence to support one as better than the other.

Paul and Lentz (1977)

Although the milieu and social learning approaches were both forms of psychosocial programming, they were vastly different. The milieu therapy approach was based upon building a sense of community and relying on social pressures to maintain expected behavior (Paul & Lentz, 1977). The social learning approach was at the crossroads of several different ideas, primarily social influence and learning in treatment contexts, schedules of reinforcement, operant conditioning ideas (Skinner, 1953), and Ayllon and Azrin's (1965) concept of a token economy. In the social learning approach, clients had a highly structured schedule and the tokens, along with social and verbal reinforcement, were used to shape and reinforce various behaviors required of the client, including interpersonal interaction, instrumental activity, self-maintenance and regulation, and individual entertainment, among others (Paul & Lentz, 1977). These tokens could then be spent on various privileges or goods (Menditto, 2002). Additionally, clients were required to take classes, many of which were used to teach skills and shape behavior (Paul & Lentz, 1977).

The program was carefully formulated to only reinforce positive behavior; clients participating at a minimal level were seldom reinforced (Paul & Lentz, 1977). Floor staff were required to document their observations of clients via a Time-Sample Behavioral Checklist (TSCB) and Staff-Resident Interaction Chronograph (SRIC). As clients met their weekly target, they were able to move up the tiered level system in place (Levels I-IV) and the tokens were used less; instead, clients would receive a weekly paycheck (later adapted to a weekly credit card; Menditto, 2002). As clients progressed, they had weekly token pay days to help them learn to plan ahead and prepare for life in the community after discharge (Paul & Lentz, 1977). Just prior to discharge, clients would receive money and demonstrate their ability to budget based on their learning in the SLP program (Menditto, 2002).

At the six-month assessment, participants had only been involved in the respective program for approximately 18 weeks due to outside issues (Paul & Lentz, 1977). Still, the results were impressive; both treatment approaches had significantly reduced the amount of bizarre and aggressive behaviors occurring in clients. Additionally, clients in both treatment groups demonstrated improved interpersonal skills and self-care. However, even at just 18 weeks, the SLP was more effective than the milieu-based approach, evidenced by every SLP resident showing significant improvement regardless of functioning, whereas approximately 75% of the milieu-based residents had significant improvement that seemed more dependent on gender and length of hospitalization. Paul and Lentz (1977) noted the continued success in both programs two years later, and again, the SLP surpassed the milieu-based approach in many areas, including superior community meetings, evidenced by the SLP participants ability to have “an overall meeting with less confusion and relatively more on-task behavior than at milieu community meetings” (p. 150). Additionally, the SLP group had reduced use of resources, including services and facilities, more time awake during waking hours, significantly improved intramural functioning, decreased bizarre and aggressive behavior, increased adherence to hygiene schedules, and increased successful discharge to the community (i.e., lasting longer than 90 days), as well as being more cost-effective. At the end of the 6-year study, Paul and Lentz (1977) concluded by saying:

> All of the most debilitated people ever subjected to systematic study whose physical condition allowed active participation in social-learning procedures achieved improvement and release with community stay. Based upon both objective and rated improvements in intramural functioning, and the remarkable absolute effectiveness in achieving release with community stay, social-learning procedures clearly emerge as the treatment of choice for the severely debilitated chronically institutionalized mental patient. (p. 383)

The Social Learning Program: 1980s-Present

Following Paul and Lentz’s (1977) study, researchers and clinicians alike were impressed with the results, which were indicative of drastic improvements in clients with histories of chronic mental illness and minimal successes in a variety of domains, including ability to care for themselves, social interactions, bizarre behavior, and most of all, reintegration with the community without subsequent, repeated hospitalizations (Glynn & Mueser, 1986). However, research investigating inpatient psychiatric treatment had waned as a whole and any new evidence on the SLP was minimal in the time that followed the 1977 book publication until 1990 (Paul & Menditto, 1992)–even though continued peer reviews of Paul and Lentz's work indicated the SLP had empirical support (Glynn & Mueser, 1986; Paul & Menditto, 1992). In the 30 years that have since followed, the SLP has proven to be an exceptional treatment modality for patients with SMI, based on a variety of studies that have been completed since.

Aggression, one of the most significant areas of concern in an inpatient psychiatric setting, has shown to be reduced in clients who participate in the SLP on civil (Bellus et al., 1999) and forensic wards, with dramatic positive effects (Beck et al., 1991; Goodness & Renfro, 2002; Menditto, 2002), along with reduced instances of the seclusion and physical restraint of clients (Goodness & Renfro, 2002; Silverstein et al., 2006). Additionally, research has suggested the SLP assists clients in increasing adaptive behaviors (Menditto et al., 1996; Newbill et al., 2011), basic skills (Menditto et al., 1991), adherence to grooming and cleanliness of one's space (Oehler et al., 2018; Silverstein et al., 2006), attentional abilities (Menditto et al., 1991; Silverstein et al., 2009), and ability to complete simple academic tasks (Menditto et al., 1991). Additionally, results across various studies indicated wards implementing the SLP had success in decreasing levels of water consumption in clients who had histories of polydipsia (i.e., abnormally great thirst; Baldwin et al., 1992), allegations of abuse and neglect made by clients (Goodness & Renfro, 2002), and general bizarre and/or inappropriate behavior (Paul & Menditto, 1992).

Menditto (2002) noted even the SLP clients who were admitted to maximum-security forensic psychiatric facilities had fared well; none of the 70+ clients transferred to less secure settings were returned to maximum-security in the year that followed their transfer. Additionally, of the 22 clients who had been released on forensic conditional releases, none of them had been arrested for subsequent offenses and only one had a revocation of his conditional release (Menditto, 2002). Furthermore, one study involving clients on a maximum-security forensic ward indicated that clients who had participated in the SLP had decreased length of stay and were more likely to be successfully discharged into the community (Goodness & Renfro, 2002).

A recent longitudinal study (Menditto et al., 2022) compared rates of discharge and rehospitalization over the course of 1988–2019 for maximum-security forensic clients who had participated in the SLP and a control group who had not. Regarding discharge, the researchers compared two groups of clients discharged between 1988–1995. Eight of 19 of SLP clients (42%) had discharged, whereas only 2 of 19 (10%) of those who had received treatment as usual had discharged. Regarding rehospitalization, the readmission rates of the SLP clients versus "other long-term treatment" clients were compared (Menditto et al., 2022, p. 7). Of the clients discharged between 2010 and 2019, 3.3% (3 of 90) of the SLP clients were readmitted to the maximum-security facility, and 14.2% (32 of 225) other clients were readmitted to maximum-security. The extant research in the last 30 years highlights the efficacy of the SLP and its effectiveness in treating individuals with SMI across a variety of contexts with successes in a variety of measurable areas.

Acknowledging the social climate of the deinstitutionalization era and the concept of social breakdown syndrome are important because they explain why interest in contemporary inpatient treatment programs arose. A thorough examination of the original SLP study is warranted to understand the approach itself and how the culmination of research led to its profound effectiveness in inpatient populations. Lastly, the extant research on the SLP in the last

30 years highlights why it continues to be considered a best practice by APA (2007) and further suggests a need to examine client subjective experiences (i.e., QoL), as the SLP has shown to be superior in most objective domains.

Quality of Life

Defining Quality of Life

Researchers have grappled with defining the construct of quality of life (QoL) since the 1960s (Campbell, 1981; Corring, 2002; Eack & Newhill, 2007; Kerce, 1992; Lehman, 1988; Ruggeri et al., 2001). Varying definitions have been posited; even in recent years, there is not one absolute definition of QoL (Karimi & Brazier, 2016). Researchers have diverged on whether subjective and/or objective information should be collected as a part of its conceptualization (Corring, 2002; Felce & Perry, 1995; Kerce, 1992; Lehman, 1988; Ruggeri et al., 2001). The World Health Organization’s most recent definition described QoL as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (World Health Organization, 2022). Conversely, other definitions include “a conscious cognitive judgment of satisfaction with one’s life” (Rejeski & Mihalko, 2001, p. 23), or Felce and Perry’s (1995) definition that QoL “integrates objective and subjective indicators, a broad range of life domains, and individual values” (p. 51). Furthermore, the terms *quality of life, health, health-related quality of life, life satisfaction,* and *subjective well-being* are often used interchangeably (Karimi & Brazier, 2016; Rejeski & Mihalko, 2001).

Due in part to the definitional variances, assessments utilized to investigate QoL often measure differing facets of the concept. The factors frequently depend on the definition the researcher believes to be correct (Karimi & Brazier, 2016; Kerce, 1992; Rugerri et al., 2001).

Additionally, Lam (2010) noted there are hundreds of subjective measures that were developed to examine QoL or facets of it; there is overlap between many of these assessment tools, as they ultimately investigate different aspects of the construct. For example, three of the most commonly used QoL tools are the World Health Organization Quality of Life assessment instrument (WHOQOL-100), World Health Organization Quality of Life Abbreviated Version (WHOQOL-BREF), and the European Quality of Life - 5 Dimensions (EuroQol EQ-5D; van de Williege et al., 2005). WHOQOL assessments specifically examine concepts of a person's life related to physical health, psychological health, social relationships, and environment (Hawthorne et al., 2006; Shawver et al., 2016). Conversely, the EuroQol EQ-5D evaluates anxiety/depression, pain/physical discomfort, self-care, physical mobility, and activities of daily living (Emrani et al., 2020). Even these popular screening tools examine different concepts and simultaneously describe the results as *quality of life.* For the purposes of this dissertation, QoL is defined as described by the World Health Organization (2022) for its subjective nature; this is an important feature in capturing the lived experiences of prospective participants (Corring, 2002; van de Williege et al., 2005). More information about QoL, as well as the WHOQOL-BREF, is included in the methodology chapter.

History of Quality of Life

Quality of life was first mentioned in Pigou's (1920) *The Economics of Welfare,* where the term was used in attempts to discuss the effects of government support for lower classes. The term did not become an important topic of discussion until the end of the second World War (Wood-Dauphinee, 1999). After World War II, the World Health Organization's (WHO) constitutional definition of health changed to include *mental well-being* for the first time (World Health Organization, 1948). The WHO constitution also noted that health is not only the absence of disease or sickness, but is also a state of "complete physical, mental and social well-being" (World Health Organization, 1948, p. 1). This prompted discussion around the world about whether the construct of health, with its recent definitional changes, could somehow be measured (Wood-Dauphinee, 1999). Conversation about QoL rapidly increased in the 1960s and was mentioned by President Johnson in 1964 in the "Report of the President's Commission on National Goals in the United States," who specifically noted, "Great Society is concerned not with how much, but with how good–not with the quantity of goods, but with the quality of our lives" (Schuessler & Fisher, 1985, p. 130). Tolman (1941) and Campbell (1981) suggested that, despite having origins in economics, QoL transformed into a psychological construct. As the country progressed and people were subjected to lower levels of poverty with the end of the second World War, individuals became more concerned with areas of well-being outside of income, including relationships, general satisfaction with life, and factors related to their environment. As Tolman (1941) had predicted at the end of World War II, the "economic man" was indeed becoming the "psychological man" (Campbell, 1981, pp. 237–238).

As QoL continued to gain popularity into the 1980s and 1990s, investigation accelerated within medical and health research; subjective perception on well-being and QoL was becoming increasingly important within the medical system (Albrecht, 1994). For example, the MEDLINE National Library of Medicine results demonstrated 40 references available on QoL between 1966 and 1974. Between 1975 and 1985, there were approximately 3,300; there were over ten thousand available references in the next time frame of 1986–May 1993 (Albrecht, 1994). In a recent (1/15/2022) MEDLINE search, the term "quality of life" yielded over 140,000 results for 2017–2022.

Quality of Life and Psychiatry

QoL research has also exponentially grown in the last 20 years in examining what roles these factors play in individuals who have serious mental illness. For example, the Eack and Newhill (2007) meta-analysis on psychiatric symptoms and QoL in schizophrenia highlighted that reduction in psychopathology typically leads to improved QoL. Additional research overwhelmingly indicates severity of symptoms is correlated with lowered QoL (Kuehner & Huffziger, 2009; van de Willige et al., 2005). There is substantial research indicating individuals who have mental illnesses typically have lower QoL results than the average population (Berghöfer et al., 2020; Dong et al., 2019), other physically ill patients (Bobes et al., 2007), and when compared with other individuals who experienced 'common mental disorders', categorized by the absence of hallucinations, delusions, and thought disorder, less severity and chronicity, and absence of more than two psychiatric hospitalizations in the last two years (Evans et al., 2007). Additionally, people with SMI are more likely to report lower QoL when depressive symptoms are present (Eack et al., 2007; Lambert & Naber, 2004; van de Willige et al., 2005), or if there are other affective issues (Nordt et al., 2007; Ruggeri et al., 2002). A recently completed meta-analysis by Dong and colleagues (2019) compared QoL, as measured by the WHOQOL, between people with schizophrenia and healthy controls. Their research indicated significantly lower QoL across several domains, including environmental, psychological, social, and physical, as well as lower QoL as participants aged.

Despite many contributing factors to lowered QoL, research has indicated that higher levels of social functioning are strongly associated with positive QoL and higher overall well-being in adults with psychotic illnesses (Nevarez-Flores et al., 2019; Tong Chien et al., 2020). Further, lower levels of unmet needs and higher rates of perceived social support were demonstrated to be significantly related to better QoL (Eack et al., 2007). Tong Chien and colleagues (2020) also indicated physical health, community living skills, and absence of negative symptoms are important to consider as areas of intervention as well in order to increase functioning prior to discharge into the community. All of these factors again suggest the SLP is an effective intervention for individuals with SMI. While there are no studies that directly have researched SLP and QoL, the factors described above all have been shown to be improved for clients who participate in SLP, including decreased psychiatric symptoms and increased psychosocial and adaptive functioning.

Exploring QoL specific to forensic psychiatry is incredibly important due to the current lack of research and the increased incidence of individuals receiving care in forensic settings (van Nieuwenhuizen & Nijman, 2009; Vorstenbosch & Castelletti, 2020). While limited research has come from within the United States, especially in the last 15 years, there are promising studies that have been conducted in Europe, particularly The Netherlands (Vorstenbosch et al., 2014), Germany (Büsselman et al., 2021), and Italy (Vorstenbosch & Castelletti, 2020). These studies have indicated clients who reside on forensic inpatient wards have mixed results when evaluating QoL (Büsselman et al., 2021). For example, one Dutch study indicated there were no relations between social relations and QoL, which is different from other populations. The authors suggested that the presence of severe psychopathology and length of admission may be some of the culprits that complicate forensic clients' relationships with others. Conversely, there were strong associations between relationship with floor staff and overall QoL, affection, and positive affect, suggesting these relationships are incredibly important for this population (Vorstenbosch et al., 2014).

Vorstenbosch and Castelletii (2020) found that 74% of their sample reported moderate to high QoL, as measured by the Forensic Inpatient Quality of Life Questionnaire Short Version (FQL-SV), a QoL measurement that has been standardized on European forensic inpatient psychiatric clients. However, the clients included in this study described dissatisfaction in domains related to sexuality, nutrition, activities, and low level of environment pleasantness. Interestingly, despite the involuntary nature of their admission, the clients generally had relative satisfaction, as well as moderate to high scores on the acceptance of living in a forensic psychiatric unit; mean length of stay was 43.9 months.

There are important implications described in the research as well. Higher client ratings on QoL and relationships with clinician reduced levels of depression, hopelessness, and suicidal ideation in clients living on forensic psychiatric wards (Büsselmann et al., 2020), and unmet needs and QoL had a significant inverse relationship (Vorstenosch & Castelletti, 2020). Furthermore, clients in a separate Dutch study (Schel et al., 2015), indicated they were unsatisfied with their ability to leave, suggesting ability to have some level of autonomy and control, and to safely have time off the ward or to have day passes are important factors for QoL.

Additionally, there are QoL instruments that have been created with specific focus on the forensic, inpatient population, specifically the Forensic Inpatient Quality of Life Questionnaire (FQL; Vorstenbosch et al., 2014), and an adapted version of the Measuring the Quality of Prison Life questionnaire (MQPL; Büsselmann et al., 2021). While these two specific measures have been validated for psychometric properties and arguably are more effective at capturing aspects related to forensic psychiatry (e.g., involuntary treatment, lack of sexual relationships, decreased autonomy and control) than conventional QoL questionnaires, they have been primarily used within Europe and would not be appropriate in a United States-based sample (Büsselmann et al., 2021; Vorstenbosch et al., 2014).

Qualitative Research, Serious Mental Illness, and Quality of Life

Garnering information on the subjective, lived experiences of people with serious mental illness has become increasingly important to better serve and aid this population. Qualitative research has been able to shed light on these experiences and provide a way for this group of people to have a voice and share their stories. Grounded theory, narrative analysis, and phenomenological analysis are all examples of qualitative research that often serve as apparatuses for researchers to collect and interpret information about these experiences (Smith et al., 2022; Zolnierek, 2011). Interpretive phenomenological analysis (IPA), a core component of this dissertation, is discussed in-depth in the methodology chapter. In short, IPA focuses on not just the lived experience of its participants, but also "how people make sense of their major life experiences" (Smith et al., 2022, p. 1). Coming to terms with living with a serious mental illness or being involuntarily hospitalized are major life experiences in themselves, but the goals of this dissertation are to closely examine what, if anything, the SLP has done for these participants in relation to their QoL and lived experiences while on this particular program, within the larger system of a high-security forensic psychiatric hospital.

While few IPA studies have been centered around a population with SMI, the research that has been collected has been enlightening and inspiring. Some of these studies have included investigations about the stigma experienced by people with schizophrenia (Knight et al., 2003), grappling with hopelessness during first episode psychosis (Perry et al., 2009), experiences of hope in mental health recovery (Murphy et al., 2022), the importance of employment opportunities for people with schizophrenia spectrum diagnoses (Pańczak & Pietkiewski, 2016), and living with a serious mental illness and navigating romantic relationships (Budziszewska et al., 2020; Redmond et al., 2010).

Additionally, IPA was selected as the qualitative methodological process in a multitude of studies geared toward examining QoL. The emergence of major life experiences, as described by Smith and colleagues (2022), whether positive or negative, often result in changes in lifestyle or outlook on life. Thus, it could be posited that these transitions cause fluctuations in described QoL, generating increased interest in studying these experiences from a subjective perspective, particularly utilizing the IPA approach. IPA research on QoL includes a wide variety of topics involving medical issues, such as terminal illnesses (Fan & Eiser, 2012; Probst et al., 2013), chronic problems like incontinence (Ortuño Esparza et al., 2018) and endometriosis (Rea et al., 2020), or diagnoses such as autism (Atherton et al., 2022) and Parkinson's (Abell et al., 2017). QoL has also been explored in individuals who are undergoing major transitions in their lives, such as retirement from elite sports (Brown et al., 2018), recent cancer diagnoses in children (Mant et al., 2019), or elderly individuals residing in assisted living facilities (Mansfield & Burton, 2020). Qualitative research, and IPA in particular, allows the researcher to thoroughly investigate participants' unique life experiences and how they have made sense of them.

A client who is receiving treatment on a highly structured inpatient program, such as the Social Learning Program (SLP) at Fulton State Hospital (FSH), is at the crossroads of many important systemic structures within society. This includes the intersection of forensic psychiatry and psychology and the person's individual and unique experiences in having a serious mental illness, along with various associated impairments. This intersection also includes the person's prior exposures to the mental health system and the correctional system, particularly within this American system that has such profound overlap between criminal justice and mental health.

Specific to clients in the SLP are the additional concepts posited by Paul and Lentz's original study in 1977 and the associated research that has been completed in the last 35 years, continuously demonstrating its efficacy in increasing desired behaviors and decreasing negative or bizarre behaviors in clients. In conceptualizing the client within this system and this specific treatment program, along with the client's distinctive strengths and weaknesses, it is essential to consider the effects these factors have on their QoL.

While QoL, in itself, has been thoroughly researched within a multitude of cultures and contexts, the limited number of studies specific to populations with mental illness is concerning. Furthermore, the general absence of United States-based research on this population, particularly in the last 15 years, compounds this problem. In addition, a sparse number of qualitative studies including individuals with SMI have been conducted, providing little information about these experiences from a subjective standpoint. These listed problems highlight the apparent gaps in research that this dissertation addressed, including (a) the lived experiences and meaning making of individuals receiving inpatient psychiatric care on a forensic basis, (b) QoL of this population within a specific treatment context, and (c) research on this population in the United States. A mixed-methods approach using interpretative phenomenological analysis (IPA) for qualitative data and the WHOQOL-BREF for quantitative data was selected for thoroughness and inclusivity. Specific details about the methodological process are included in the subsequent chapter.

Research Question

The research question for this study was, "What is the quality of life (QoL) for individuals residing in a forensic hospital with diagnoses of schizophrenia spectrum disorders who participate in the Social Learning Program (SLP)?" This question was investigated from both quantitative and qualitative approaches, both of which are detailed in the subsequent methodology chapter.

CHAPTER III: RESEARCH METHODOLOGY

This project's aim was to investigate the QoL of clients at Fulton State Hospital who are participating in The Social Learning Program (SLP) and to explore their lived experiences. It was conducted through a mixed-methods research design (Creswell & Creswell, 2018; DeCuir-Gunby & Schutz, 2017), with an overarching interpretative, phenomenological, and hermeneutic framework (i.e., Interpretive Phenomenology Analysis; IPA). The primary purpose of this study was to answer the following question from both quantitative and qualitative perspectives:

RQ1: What is the quality of life (QoL) for individuals residing in a forensic hospital with diagnoses of schizophrenia spectrum disorders who participate in the Social Learning Program (SLP)?

To effectively address this research question, I took a mixed methods approach, which has a central premise "that the use of quantitative and qualitative approaches in combination provides a better understanding of research problems than either approach alone" (Creswell & Plano Clark, 2007, p. 5). In accordance with the Interpretive Phenomenological Analysis (IPA) data collection strategy, a semi-structured interview was conducted to garner responses on lived experiences, QoL, and meaning making. The WHOQOL-BREF was used to gather quantitative data and various descriptive statistics were run via SPSS to examine the data, along with demographic information collected about the participants. The various documents included in this process, including recruitment letters and informed consents for participants and their respective guardians, can be found in Appendices A–D.

Although a qualitative project would have likely been sufficient in garnering responses, negative symptoms of diagnoses typically included in the umbrella of SMI can lead to lasting thought impoverishment, response latency, and difficulty articulating oneself (Krynicki et al., 2018). A mixed-methods approach seemed most appropriate in that I was able to collect responses (via the WHOQOL-BREF) from individuals who had difficulties articulating themselves verbally, rather than excluding those that would not have been able to fully participate in an interview. This proved to be an effective strategy, as most of the participants did experience some level of difficulty with the interview and articulating themselves. Some interviews were shortened due to the apparent latency and poverty of speech, restlessness and impatience to end the interview, and medication side effects (i.e., falling asleep during the interview). Therefore, this dissertation utilized a convergent parallel mixed methods design (qualitative and quantitative). In this type of design, the “quantitative and qualitative data are collected concurrently but separately; the data analyses are merged…. [This] creates a comprehensive analysis and discussion” (DeCuir-Gunby & Schutz, 2017, pp. 87–88).

Methods and Procedures

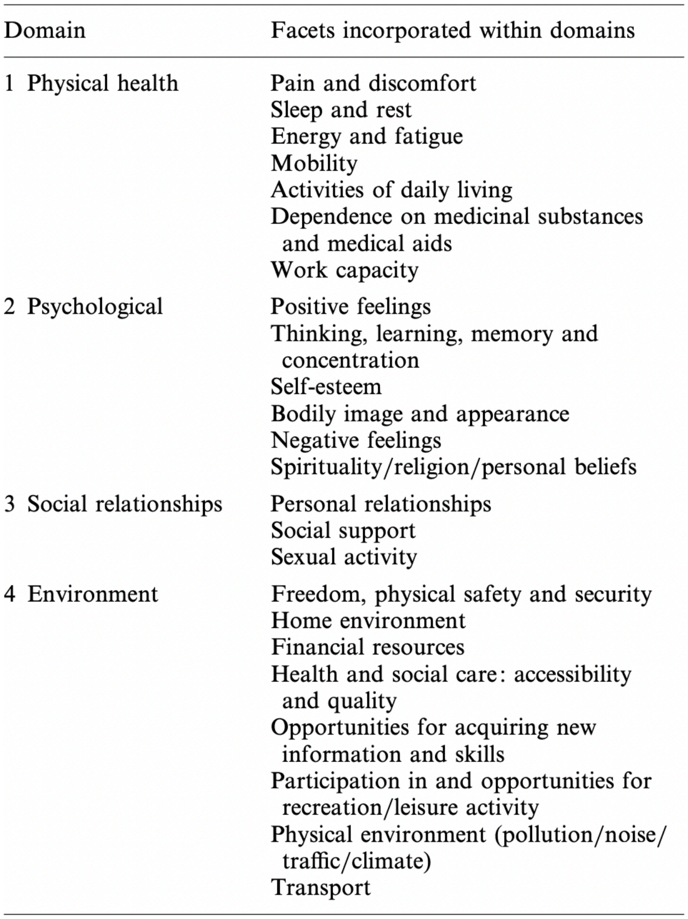
Quantitative Method: WHOQOL-BREF

The WHOQOL-BREF was selected for ease of use, short administration time, and utility in describing QoL, based on prior research (Corring, 2002; van de Williege et al., 2005; World Health Organization, 2022). Additionally, regarding required reading level, the WHOQOL manual (WHO, 2012) states, “The WHOQOL-BREF should be self-administered if respondents have sufficient reading ability; otherwise, interviewer-assisted or interview-administered forms should be used” (p. 49). All of these factors suggested this was an appropriate measure for this sample. I received permission to use the WHOQOL-BREF for my dissertation on May 23, 2022 from the WHO QoL Research group, which is included in Appendix E.

The WHOQOL-BREF has four domains related to QoL: physical health, psychological health, social relationships and environment. Figure 3.1 describes the components that comprise these four domains. The WHOQOL-BREF also includes one facet covering overall QoL and general health.

Figure 3.1

WHOQOL-BREF Domains (The WHOQOL Group, 1998, p. 552)



Domain	Facets incorporated within domains
1 Physical health	Pain and discomfort Sleep and rest Energy and fatigue Mobility Activities of daily living Dependence on medicinal substances and medical aids Work capacity
2 Psychological	Positive feelings Thinking, learning, memory and concentration Self-esteem Bodily image and appearance Negative feelings Spirituality/religion/personal beliefs
3 Social relationships	Personal relationships Social support Sexual activity
4 Environment	Freedom, physical safety and security Home environment Financial resources Health and social care: accessibility and quality Opportunities for acquiring new information and skills Participation in and opportunities for recreation/leisure activity Physical environment (pollution/noise/traffic/climate) Transport

The items are rated on a 5-point Likert scale, with a 1 indicating “very dissatisfied, very poor, or not at all,” depending on the question posed, and a 5 indicating “very satisfied, very good, or completely,” depending on the question posed. The entirety of the WHOQOL-BREF and all questions are included in Appendix F. A higher score in each of these domains and the overall domain indicates better QoL. Additionally, research has indicated the WHOQOL-BREF is more sensitive to psychological and social well-being than the EuroQoL EQ-5D over time (van de Williege et al., 2005), and the WHOQOL-BREF has been used in research in a variety of contexts, cultures, and populations. Internal consistency is found to be acceptable (Cronbach's alpha = 0.66-0.84, with the lower Cronbach's alphas related to social relationship domains; Harper et al., 1998). Additionally, construct validity has been assessed and confirmed via confirmatory factor analysis (Chen et al., 2009; Oliveira et al., 2016). Specifically, Oliveira and colleagues (2016) determined items of the WHOQOL-BREF significantly correlated with their domains and that no item was more strongly correlated to a different domain than to its own.

Research on the content validity of the WHOQOL-BREF has indicated there are several items that may confound with the meanings of other domains (e.g., "items from the environmental domain confounded with psychological and social domains;" Yao et al., 2008). Thus, Yao and colleagues (2008) posited that researchers may need to evaluate the meanings of the items from the participants' viewpoints. Although there is no gold standard for QoL assessments, in order to assess criterion validity of the WHOQOL-BREF, researchers have used various instruments with distinct concepts that can still be correlated. These analyses have found the WHOQOL-BREF's criterion validity to be satisfactory (Castro et al., 2007; da Silva Lima et al., 2005).

While there are apparently no existing studies in the United States to provide norms for QoL in long-term inpatient clients, there is existing literature from Europe that has indicated the WHOQOL-BREF is a valid and reliable instrument for measuring QoL in inpatient psychiatric samples (Oliviera et al., 2016), as well as individuals with SMI (Adewuya & Makanjuola, 2009; Berghöfer et al., 2020; Meepring et al., 2021; Tong Chien et al., 2020). Additionally, the

WHOQOL-BREF has been found to provide reliable and valid results when examining QoL in a population of “homeless, substance dependent veterans” in the United States (Garcia-Rea & LePage, 2010, p. 339).

Qualitive Method: Interpretive Phenomenological Analysis

Interpretive Phenomenological Analysis (IPA) sits at the intersection of three theories, phenomenology, hermeneutics, and idiography. IPA draws on key concepts drawn from each of these three approaches and will be described in depth because “[t]he underlying philosophy of IPA is just as important as matters of procedure” (Smith et al., 2022, p. 5).

At its very core, phenomenology is simply an approach to the study of experience (Smith et al., 2022). Despite variation between phenomenological approaches, phenomenologists have one thing in common, understanding the human experience. Husserl, who proposed the founding features of phenomenology, argued this process involves careful examination of the human experience, and in “the way it occurs, and in its own terms” (Smith et al., 2022, p. 12). By stepping outside of the everyday experience and reflecting on this outside of the individuals’ consciousness, one is being phenomenological. Further, Husserl approached phenomenology from a descriptive lens, which is the “bracketing,” or setting aside one’s preconceived knowledge, such as assumptions, judgments, or values (Smith et al., 2022, p. 12). Husserl additionally posited different “modes of consciousness” (Husserl, 1927, para. 3), in which the phenomenon is processed through different lenses (described as “reductions”), therefore leading to an all-encompassing, raw understanding of the phenomenon without the preconceived notions, assumptions or judgments (Smith et al., 2022, p. 14).

Husserl’s student, Heidegger, eventually moved away from Husserl’s conceptualization, finding that Husserl’s work was too theoretical and abstract. Rather, Heidegger was more interested in the experience of human existence, and how that experience is made meaningful. Heidegger’s branching out from the original concepts of Husserl’s phenomenology marked the beginnings of hermeneutics and the emphasis of existential application within phenomenological philosophy. Heidegger’s views included intersubjectivity, or the view that humans’ engagement with the world is overlapping and relational. He believed that people are mistaken if they believe they can separate themselves completely from this relationship with the world (Smith et al., 2022).

The third and final component to interpretative phenomenological analysis (IPA) is idiography, which can be summarized as being concerned with the particular. Idiography influences in two distinct ways, the first of which lies in detail, and therefore, depth of analysis. Secondly, IPA incorporates idiography by examining the way a particular group of people experiences a particular phenomenon in a particular context (i.e., understanding the experience of a homogenous group of people who are experiencing the same phenomenon). Though the IPA researcher is investigating these experiences as a whole, they are careful to analyze each participant’s experience before moving on to the next (Smith et al., 2022), as the experiences will be compared and contrasted during the analysis process. As described by Miller and colleagues (2018), in addition to the aforementioned components, IPA also incorporates other phenomenological frameworks, “infusing the philosophical tenets of Merleau-Ponty, Sartre, Schleiermacher, and Gadamer to focus on (a) existential meaning; (b) the constant interaction between participant and context; and (c) the emphasis on historical, contextual, and political forces on participants” (p. 241). Lastly, IPA utilizes a “double hermeneutic” approach, which is the idea that while the researcher is collecting participants’ responses, interpreting the data, and describing the participants’ lived experiences, the researcher is simultaneously making sense of their own experience with the participants (Smith et al., 2022, p. 35).

Using an Interpretive Phenomenological Analysis (IPA) framework was best suited for this project because of multiple factors, including my desire to understand the lived experience of these individuals, their QoL, and meaning making. In addition, IPA emphasizes an idiographic approach to both the unique and collective experience of each person’s journey to the SLP. Lastly, the “double hermeneutic” nature of IPA, which suggests that the researcher makes sense of the participants’ experiences while simultaneously examining and making sense of their own experience and reflecting on the relationship (Smith et al., 2022, p. 35). I also appreciated Smith and colleagues’ (2022) emphasis on reflexivity, or the idea that qualitative research, and thus, IPA, are largely interpretations that are “based on the cultural, social, gender, class, and personal politics that we bring to research” (Creswell & Poth, 2018, p. 228). As such, I kept a reflexive log about my preconceptions and views of the mental health system, serious mental illness and related symptoms, and the Social Learning Program. I continued to make reflexive comments as the study progressed, after I left Fulton State Hospital, and as I began creating transcriptions of the recorded interviews and conducting analyses.

Participant Selection

IPA methodology calls for a reasonably homogenous sample (Smith et al., 2022); however, the sample pool itself was reasonably homogenous because of the strict criteria for a client to be admitted to the Social Learning Program. Thus, I did not purposefully select particular members.

All participants were admitted clients of Fulton State Hospital (FSH) in Fulton, Missouri, on the Social Learning Program (SLP). An admission to the SLP at FSH requires a diagnosis of serious mental illness (SMI) for longer than one year with multiple hospitalizations, and/or with failed attempts at community reintegration. Additional admission criteria to the SLP include severe deficits in social skills, self-care, and/or instrumental performance, and high rates of exhibited bizarre behavior. Clients residing on the SLP may have a concurrent diagnosis of personality disorder, but it may not be a primary diagnosis or reason for hospitalization. The admission criteria for the SLP coincided well with the Ruggeri and colleagues' (2000) conceptualization of SMI that was used for this project; both included focus on significant impairment of functioning, diagnosis, and duration, which was implied due to criteria for and length of admission.

All participants in the study had, at some point following their admission to the Social Learning Program (SLP), achieved Level II. Level II status on the SLP entails increased completion of tasks related to cleaning up after self, maintaining adequate hygiene, interactions with others, attending and participating in scheduled groups, activities, and leisure events, as well as no intolerable infractions (i.e., aggressive, sexual, or other inappropriate behaviors). Clients who maintain these increases for two weeks will obtain Level II status, which comes with increased privileges as well. Clients who continue their treatment gains will advance to Level III and then to Level IV status and additional privileges.

Lastly, while the WHOQOL-BREF is available in 19 languages, I am only fluent in English, so potential participants were excluded if they did not have fluency in English. Regarding reading level, I did not exclude any potential participants based on their described reading level or ability, based on the ability to read questions out loud, as instructed by the manual. I asked each participant if they had difficulty with reading prior to giving them the recruitment letter. If they indicated they could not read the letter, I read all items (e.g., the recruitment letter, informed consent, and WHOQOL-BREF) to them out loud. The screening questions regarding obtaining Level II status at some point during the admission and English fluency can be found in Appendix G.

Of the 75 residents at Fulton State Hospital with diagnoses of schizophrenia spectrum disorders, 56 were not capable to participate because they had never progressed beyond a Level I or were too psychotic or disorganized to participate, as determined by Dr. Alicia Pardee, Assistant Director of Treatment Services and Director of Psychology at Fulton State Hospital. Of the remaining 19, one was not eligible because of inability to understand the English language and seven were excluded because they or their guardians declined the consent to participate. Therefore, the final sample size for the present study was 11 (N = 11).

Sample Characteristics

Table 4.1 includes demographic details regarding the eleven participants of the present dissertation.

Protection of Human Rights

Risks

Individuals who have lived experience of serious mental illness (SMI) are particularly vulnerable. The fact that they are receiving treatment involuntarily in an institution makes this especially true. I have worked with this population for the last five years and was particularly aware of these vulnerabilities and the risks that the present dissertation could bring. Varied questions about their experiences within this psychiatric system could have brought up negative emotions, feelings, or memories. Participants could experience loneliness, sadness, anxiety, or other general distress when recalling their journeys and how they have made sense of their journeys in conjunction with the quality of their life. It could have also brought up feelings about their histories or reason for admission. Reminding individuals of their negative experiences could also bring up thoughts, urges, or impulses to act out violently toward themselves or others. From a social standpoint, it may feel intrusive to have a researcher accessing sensitive information, whether in the interviews or via archival records.

Because all participants in this study were particularly vulnerable, I took proactive steps taken to ensure all participants were protected. I familiarized myself with the Fulton State Hospital policies and procedures regarding reporting comments and/or behavior about suicide, self-harm, aggression, or sexual offending, and notified all participants I was required and prepared to collaborate with their treatment teams if this came up in our discussions. No participants made any comments regarding suicide, self-harm, intent or plan to harm others, or sexual offending. No deception nor invasive procedures were used in this dissertation. Due to potential risks associated with participating in this dissertation, I encouraged participants to discuss any distress with their treatment team and offered them an opportunity to speak with me an additional time if there was anything bothering them from our interview. None of the participants contacted me for additional support after the completion of involvement in the study. Lastly, informed consent was acquired from both study participants and their guardians (Appendix A–Appendix D).

Benefits

There were several potential benefits to the participant for participating in this research project The primary benefit for participants included a financial incentive, depending on their level of participation ($5 for completing the WHOQOL-BREF and an additional $10 for completing the interview, if applicable). Another potential benefit for participants was increased knowledge and understanding about QoL and how this is measured. Additionally, they could garner a better understanding about their own experiences in the SLP and how they have impacted them.

The anticipated benefits of this dissertation were to expand the current understanding about QoL in forensic inpatient clients who participate in SLP; while it is the first study to examine QoL in those who participate in this specific modality of treatment, this dissertation also appears to be the first to examine QoL in forensic clients in the United States. Participants may also experience feelings of achievement and meaning at contributing to this research and the possible considerations that their participation may bring.

Privacy and Confidentiality

The proposal of this dissertation was sent to the Institutional Review Board (IRB) at Antioch University Seattle and was approved November 1, 2022. It was then sent to the Fulton State Hospital Research Committee and was approved November 14, 2022. It was then forwarded on to the PRC at the State of Missouri’s Department of Mental Health and was approved on February 10, 2023. No participants were involved in the dissertation, nor were any contacts made prior to the approval of all three.

Confidentiality was maintained from the start of the research process. I codified all participants’ names after the informed consent was completed. Only I had access to the participants’ actual names and demographic information, which was retrieved from a review of the participants’ medical and archival records after the interviews (see Appendix H for information collected). All of the signed informed consents and information related to the participants’ identities were stored in a physical file and then scanned into a computer file, which is on my password-protected computer.

Although all information was codified and de-identified, it is likely that some of the comments included in the results and/or discussion section could be recognizable to the participant. I informed all participants that quotes, paraphrases, and summarizations are often used in qualitative research projects (Smith et al., 2022) and the participant had the option to let me know if this was not okay with them. None of the participants declined to have this information included in my dissertation. Since the study is completed, all data will be deleted from my computer in one year.

Data Collection

Eleven participants who resided on the Social Learning Program (SLP) at Fulton State Hospital (FSH) participated in this study. These 11 participants had all obtained a Level II at some point during their admission to the SLP. Three participants were their own guardian and were cognitively able to provide oral and written consent to participate in this study. The remaining eight participants had guardians and I, through the assistance of the treatment teams, obtained the appropriate consent from their respective guardians. In addition, all participants provided verbal consent and most provided written consent to participating, although only their assent was required (if a participant with a guardian was unwilling to sign the consent form, I did not pressure them or require them to sign, as it was not legally or ethically required). No participants were excluded based upon their race, ethnicity, gender identity or expression, disability, age, marital status, national origin, sexual orientation, socioeconomic status, religion (creed), or military status.

Data collection took place in person on the three living areas of the Social Learning Program at Fulton State Hospital. Prior to collecting data, I (and one of the SLP psychologists) talked with each of the clients selected for the study, presented the recruitment letter, and provided clarification about the intention of the study and the monetary incentive ($5 for completion of the WHOQOL-BREF questionnaire and $15 for the questionnaire and the survey; the incentive was then paid through coordination with the accounting office). If the client indicated they were interested, I went over the formal consent form with them, let them know their guardian had given their consent, when indicated, and obtained the participants' verbal consent. Participants with a guardian who were willing to sign the consent form did so and later received a copy. All participants who were their own guardian completed the verbal and written consents and also received a copy.

After the WHOQOL-BREF was completed, I had an additional conversation with each participant, reminding them that the interview would be recorded and asked again for verbal consent before starting the interview. All participants were told they could leave at any point, without explanation and without any negative consequences. Prior to beginning the interview, each participant was informed that they could refuse to answer any question or decline to participate further at any point in the interview. One participant declined to complete the interview and voiced that they did not want to be audio recorded.

Although this study did follow the general IPA guidelines suggested by Smith and colleagues (2022), the semi-structured interview was modified due to difficulties related to participant comprehension and their ability to answer (see Appendix I for the semi-structured interview schedule). The semi-structured interview included several open-ended questions posed toward the subjective experiences of the participant as they specifically relate to the SLP and how they experience their QoL. It also included open-ended questions that expanded on questions posed in the WHOQOL-BREF related to physical health, psychological health, social relationships, and environment. I attempted to ask each of the questions as described in the interview schedule, but sometimes varied from the script due to difficulties with the participants' ability to respond, including responding to unseen stimuli during the interview, tangentiality, and loose associations. While the modification of questions did not change the content of what was being asked, the questions were more guiding than would be typical of IPA and certain aspects (e.g., mood, relationships with others, tokens and levels on the Social Learning Program) were explicitly asked about. Thus, there was less spontaneity in answers provided, which, in turn, impacted the coding and analysis process as well. These limitations are expanded upon in the discussion chapter.

Analysis

As informed by Creswell and Creswell (2018), there are three distinct phases when analyzing data in convergent mixed methods designs. First, the qualitative data will be coded and themed using the IPA data analysis steps as proposed by Smith et al. (2009), which will be described below. Second, in accordance with Creswell and Creswell (2018), the quantitative data will be analyzed using descriptive analyses. The third step of this process will be the "mixed methods data analysis," which consists of integrating the qualitative and quantitative result (Creswell & Creswell, 2018, p. 219), and will be described in the Discussion Chapter.

Quantitative Data Analysis

Demographic descriptive information on age, gender, race, education, mental/physical health diagnoses, number of admissions to FSH, length of current admission, guardianship status, and civil versus forensic status are reported in the results chapter. WHOQOL-BREF scores are expressed as mean values, with variability expressed as standard deviation (*SD*) in text and standard error of the mean (SEM) in a figure.

WHOQOL-BREF overall score, Physical Domain, Psychological Domain, Social Relations Domain, and Environmental Domain were each contrasted versus the scale mean (“3” on the 1 to 5 scale) and versus published normative values using analysis of variance (ANOVA). The Overall WHOQOL-BREF was contrasted to published “good-poor” normative threshold value of 3.4 (Silva et al., 2014). The WHOQOL-BREF domains scores were contrasted with the WHO’s (1997) normative values of 3.67 for the Physical Domain, 3.94 for the Psychological Domain, 3.93 for the Social Domain, and 3.91 for the Environmental Domain (WHO, 1997). Lastly, domain scores were contrasted versus each other using ANOVA. All ANOVA results include the p-value to determine statistical significance. Results were considered statistically significant at the $p < .05$ threshold. Quantitative data were analyzed in SPSS statistical software (version 23, IBM Inc., Chicago, Illinois).

Qualitative Data Analysis

Shortly after the interviews were completed and all information was collected, I hand-transcribed all recordings. However, correctly transcribing the interviews proved to be challenging, with various statements by many participants being incomprehensible. Although I had a colleague review my transcriptions for clarity and thoroughness, they were also unable to decipher certain statements as well. All recordings, transcriptions, and collected demographic information are in a data storage file on my password-protected computer and will be destroyed after my defense is completed.

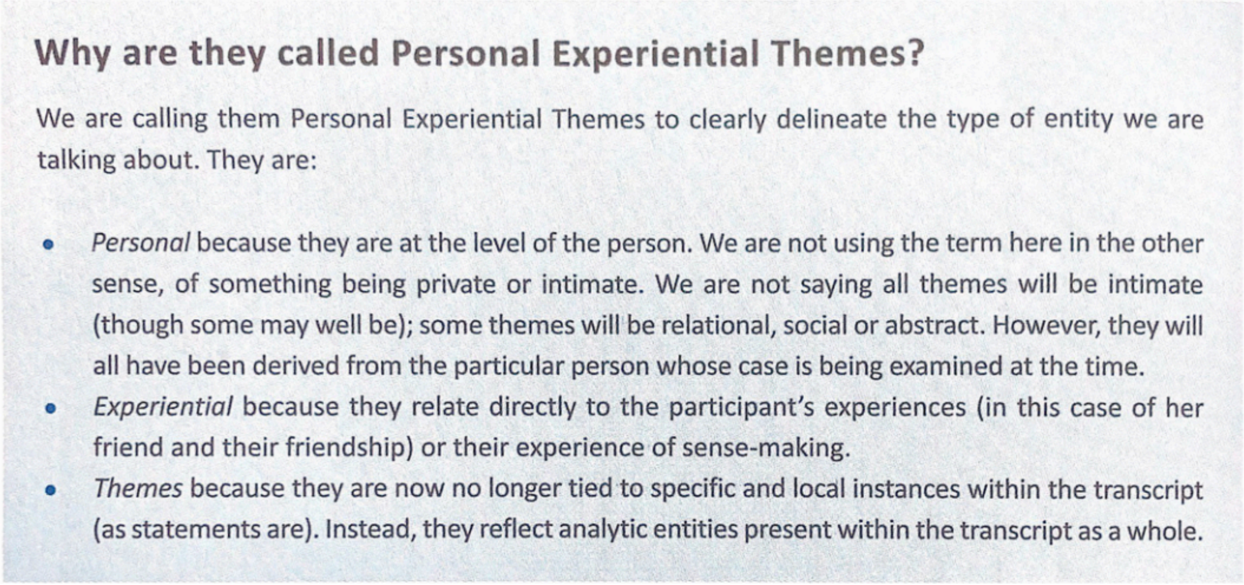
While IPA does not include one prescriptive way to work with data collected in the interviews, Smith and colleagues (2022) offer a “hermeneutic framework for analysis” that integrates strategies utilized by other IPA researchers (p. 76). As such, I used these flexible guidelines proposed by Smith et al., which includes six steps, all thoroughly and fully applied to each participant before moving on to the next. The first step of analyzing the data is “Reading and Re-Reading” (Smith et al., 2022, p. 78). Repeated reading allows the researcher to be more engaged with the participant’s experience. As suggested by Smith and colleagues, after I completed the transcriptions, I listened to the participant’s interview while also reading the transcriptions and making observations of my own experience during the interviews and writing them in a separate notebook.

The second step is “Exploratory Noting” (Smith et al., 2022, p. 79), which included closely reading the transcript and make detailed notes about the data. The aim of this step was to begin to understand the way the participant “talks about, understands and thinks about an issue” (p. 79); however, it is exploratory, so I avoided focusing on the *why* of the participant’s experience. I made comprehensive comments about the transcript to aid the next step (3) of the analysis, which is “Constructing Experiential Statements” (Smith et al., 2022, p. 86). During this third step, I aimed to reduce volume of detail “while maintaining complexity” (p. 86), meaning I articulated the most important features of the exploratory notes that were made in the previous step, though these notes should still be very closely connected to the original transcript. This step marked the shift from exploratory review to analysis, in which I began the hermeneutic circle by making experiential statements, or the participant’s experiences or “experience of making sense of the things that happened to them” (p. 86).

Next, the fourth step of the analysis proposed by Smith and colleagues (2022) is “Searching for Connections Across Experiential Statements” (p. 90). During this step, I gathered the transcripts with the exploratory notes and experiential statements. I then searched for connections between the various experiential statements and clustered those together, always keeping in mind the question of the participant’s experience and their world, and if the clusters being presented are reflective of that process. The next step (5) is "Naming the Personal Experiential Themes (PETs) and Consolidating and Organizing Them in a Table" (Smith et al., 2022, p. 94). The step began by giving a title to the clusters that were created in step 4; the title described the characteristics of each cluster. Figure 3.2 encompasses the descriptions of PETs from Smith and colleagues.

Figure 3.2

Personal Experiential Themes (Smith et al., 2022, p. 94)



Why are they called Personal Experiential Themes?

We are calling them Personal Experiential Themes to clearly delineate the type of entity we are talking about. They are:

- *Personal* because they are at the level of the person. We are not using the term here in the other sense, of something being private or intimate. We are not saying all themes will be intimate (though some may well be); some themes will be relational, social or abstract. However, they will all have been derived from the particular person whose case is being examined at the time.
- *Experiential* because they relate directly to the participant's experiences (in this case of her friend and their friendship) or their experience of sense-making.
- *Themes* because they are now no longer tied to specific and local instances within the transcript (as statements are). Instead, they reflect analytic entities present within the transcript as a whole.

The last step (6) is "Continuing the Individual Analysis of Other Cases" (Smith et al., 2022, p. 99), in which the process was repeated for all cases. When Steps 1–5 have been completed for all individual cases, a seventh step was then completed, titled "Working the Personal Experiential Themes (PETs) to Develop Group Experiential Themes (GETs) Across Cases" (Smith et al., 2022, p. 100). The last step was quite involved and required me to look for patterns and the similarities and differences that have collectively emerged across the PETs that were created through the analysis of all cases. These PETs then became the GETs of the dissertation. There were numerous PETs, so I practiced flexibility throughout this step in aligning PETs with the most appropriate GET or created a new GET.

Reliability/Credibility

Establishing reliability and credibility in mixed methods research is incredibly important (Decuir-Gunby & Schutz, 2017). The reliability of the WHOQOL-BREF was calculated using reliability analyses (Cronbach's alpha), which is a measure of internal consistency (Creswell & Creswell, 2018).

Intercoder Agreement

This will be the primary way that the reliability of the qualitative data will be established. There were two coders for this project (me and a doctoral-level colleague who is also familiar with IPA). Additionally, there were involved discussions after the coding process, which assisted in "determining what exactly the coders agree on, whether they seek agreement on the code names [and subsequent PETs and GETs for IPA research], the coded passages, or the same passages the same way" (Creswell & Poth, 2018, p. 264). The following steps are also posed by Gibbs (2007) in augmenting the reliability of qualitative data: transcription checking (i.e., making sure no obvious mistakes are present), coordination and communication between researchers and code cross-checking.

Essential Qualities

Yardley (2000) posed the following characteristics as being essential to the development of good qualitative research, which can be seen in the Figure 3.3. I included all of these facets in my dissertation, with the dissertation chair and committee acting as auditors.

Figure 3.3

Characteristics of (Good) Qualitative Research (Yardley, 2000, p. 219)

Sensitivity to context
Theoretical; relevant literature; empirical data; sociocultural setting; participants' perspectives; ethical issues.

Commitment and rigour
In-depth engagement with topic; methodological competence/skill; thorough data collection; depth/breadth of analysis.

Transparency and coherence
Clarity and power of description/argument; transparent methods and data presentation; fit between theory and method; reflexivity.

Impact and importance
Theoretical (enriching understanding); socio-cultural; practical (for community, policy makers, health workers).

Validity/Trustworthiness

Establishing the validity, or "trustworthiness" in research, particularly a mixed methods study, is essential (DeCuir-Gunby & Schutz, 2017, p. 121). Validity in quantitative research examines whether the researcher is actually measuring what they described measuring and typically includes content validity, criterion-related validity, and construct validity. The validity of the WHOQOL-BREF was demonstrated earlier in this chapter.

In qualitative research, proving results are trustworthy involves ensuring "the research findings seem accurate or reasonable to the people who were studied" (LeCompete, 2000, p. 152). I followed the suggestions of Creswell and Poth (2018) by using at least two validation strategies specific to qualitative research: reflexivity, thick, rich descriptions, and prolonged engagement and persistent observation in the field (Lincoln & Guba, 1985).

Reflexivity

As mentioned earlier in this chapter, I began a reflexive log prior to the start of data collection and continued it as my dissertation progressed. I wrote particularly often during the data collection and analysis portions of this process. The log included my preconceptions, biases, reactions, and reflections.

Thick, Rich Descriptions

Creswell and Poth (2018) indicated thick, rich descriptions are a way of adding validity and trustworthiness to qualitative research. Thick, rich descriptions are created when the researcher describes the participants, situation, and setting in great detail. These, in turn, allow the reader to make conclusions about the transferability of the results based on "shared characteristics." As suggested by Creswell and Poth (2018), I revisited the data shortly after collecting it and added any descriptions that might be helpful, such as descriptions about the site, atmosphere, and culture.

Prolonged Engagement and Persistent Observation in the Field

As indicated by Creswell and Poth (2018), this validation strategy involves the researcher spending as much time in the field as possible, familiarizing themselves with the site, atmosphere, and participants prior to completing the research, and building rapport with both the gatekeepers and the participants. Becoming familiar with the context of the field allows the researcher to check for misinformation "introduced by themselves or by informants" (Creswell & Poth, 2018, p. 262). While I was at Fulton State Hospital, I spent several hours in the milieu, attending groups, familiarizing myself with Missouri's laws and statutes surrounding forensic statuses and the guardianship process, and attending treatment team meetings. In addition, after interviews were completed, I also spent a generous amount of time reading about each participant's history and how they came to reside on the SLP. Lastly, concurrent utilization of a reflexive log also helped me to check for biases and reactions that could arise throughout this process as well.

CHAPTER IV: RESULTS

Qualitative and quantitative approaches were utilized concurrently to explore the QoL and lived experiences of individuals receiving treatment on the Social Learning Program at Fulton State Hospital. This chapter will include information about the sample for the current study, followed by the quantitative findings. I will then describe the qualitative results, including detailed descriptions of the Personal Experiential Themes (PETs) and the resulting Group Experiential Themes (GETs) of the study.

The study included 11 total participants. In addition to the demographic information included in Table 4.1, all participants had a diagnosis of a schizophrenia, schizoaffective disorder, or unspecified schizophrenia spectrum disorder. The majority of participants (73%) had a court-appointed guardian. At the time of the study, five of the 11 participants (46%) were on forensic status, either Not Guilty by Reason of Insanity (NGRI) or Permanently Incompetent to Stand Trial (PIST). The remaining six participants' statuses were Voluntary by Guardian, meaning that their appointed guardians had consented to them voluntarily receiving treatment at Fulton State Hospital. The majority of the participants with a guardian were previously found Permanently Incompetent to Stand Trial by the Missouri court system. Length of admission time ranged between 1.9 and 36.6 years, with mean length of admission at 9.8 years. Length on the SLP ranged between 0.4 and 11.9 years, with mean length of time on the SLP at 4.5 years.

Table 4.1

Participant Characteristics

Code	Age	Race	Gender	Educ	Years Admin	Years SLP	Current Level	Highest Level	Medical Conditions	Additional Psych Dx
1A	61	W	Male	12	5.1	0.5	II	IV	5+	Alcohol Use D/O
2B	63	AA	Male	8	2.2	2.0	II	IV	5+	ID Moderate; Antisocial PD
3C	54	AA	Male	10	11.6	10.9	III	IV	3	Antisocial PD; Alcohol Use D/O
4D	65	W	Trans-Female	8	36.6	9.5	IV	IV	3	Alcohol, Amphetamine, Cocaine Use D/Os
5E	52	W	Female	11	1.9	0.4	III	III	0	Unspecified Substance Use D/O
6F	46	AA	Male	12	10.6	4.2	IV	IV	2	Borderline Intell. Functioning
7G	38	AA	Female	8	3.5	0.5	IV	IV	2	N/A
8H	51	AA	Female	12	11.9	11.9	I	III	2	Alcohol, Cannabis, Cocaine Use D/Os; Unspecified PD
9I	41	AA	Female	9	3.6	2.1	I	III	2	Cannabis, Amphetamine Use D/Os
10J	63	AA	Male	9	10.3	3.6	I	III	5+	Antisocial PD
11K	58	AA	Female	12	8.2	3.6	I	III	4	Cannabis, Alcohol Use D/Os; Unspecified PD; Borderline Intell. Functioning

Quantitative Results

Eleven individuals participated in completing the WHOQOL-BREF. SPSS was used to calculate descriptive statistics. The results of the WHOQOL-BREF are presented below, with domain results presented in Table 4.2.

Table 4.2

WHOQOL Domain Results by Participant

ID	Overall	Domain 1 Physical	Domain 2 Psychological	Domain 3 Social Relations	Domain 4 Environmental
1A	2.50	2.43	4.17	2.33	2.63
2B	1.50	2.57	3.83	4.00	3.00
3C	4.00	3.00	3.67	2.00	3.14
4D	2.50	3.00	2.83	2.33	3.00
5E	5.00	4.00	5.00	5.00	4.75
6F	5.00	4.57	4.83	5.00	5.00
7G	4.00	4.14	3.67	4.00	3.50
8H	4.00	2.71	3.67	4.00	3.00
9I	3.50	3.29	4.50	3.67	3.88
10J	4.00	3.29	4.00	3.67	4.00
11K	4.50	4.00	4.17	3.67	3.50

WHOQOL-BREF items are rated on a 5-point Likert scale, either from “very dissatisfied" to “very satisfied,” “very poor” to “very good,” or “not at all” to “completely,” depending on the question posed. A score of 3 would indicate a neutral response, described as “neither good nor bad,” “neither satisfied nor dissatisfied,” or “a moderate amount.” WHOQOL scores for each item are provided in Appendix J.

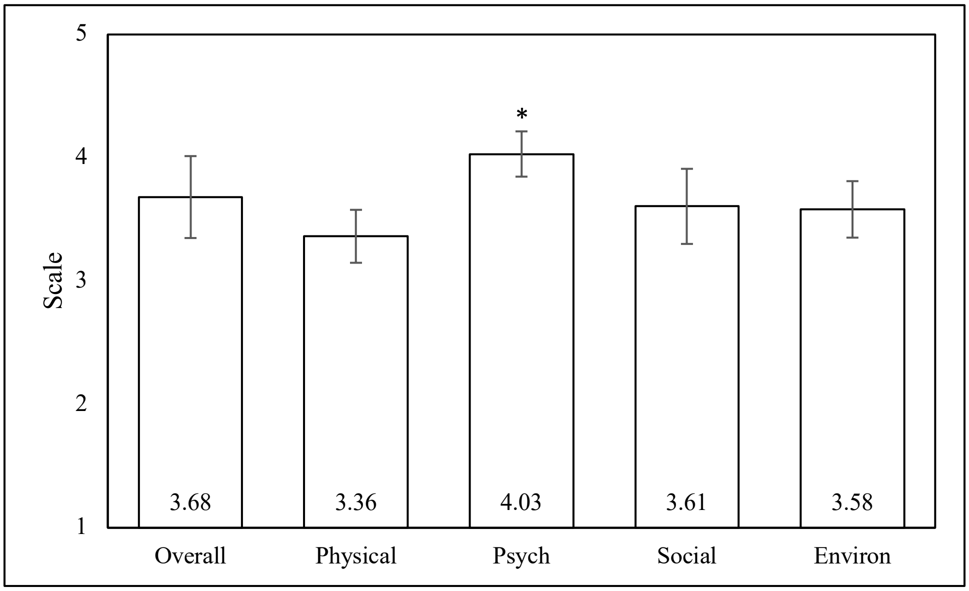
Figure 4.1 shows that average scores for all domains were above the scale midpoint. The overall WHOQOL-BREF QoL composite scores (*M* = 3.68, *SD* = 1.29) averaged somewhat above the “poor-good” threshold (3.4) of Silva et al. (2014), but this difference was not statistically significant (p = .32). However, it is important to note that 8 of 11 study participants scored above the 3.4 “poor-good” threshold of Silva et al. (2014) in overall WHOQOL-BREF QoL composite scores (Appendix J).

Physical domain scores (*M* = 3.36, *SD* = 1.31) averaged significantly lower than the WHO (1997) normative value of 3.67 (p < .05). Psychological domain scores (*M* = 4.03, *SD* =

1.31) averaged somewhat higher than the WHO (1997) normative value of 3.94 (p = .47). Social domain scores (*M* = 3.61, *SD* = 1.17) averaged somewhat lower than the WHO (1997) normative value of 3.93 (p = .12). Environmental domain scores (*M* = 3.59, *SD* = 1.21) averaged significantly lower than the WHO (1997) normative value of 3.91 (p < .02). Participants scored significantly higher in the Psychological ("Psych") domain than in the Physical domain (p < .01) and the Environmental domain (p < .05).

Figure 4.1

WHOQOL-BREF Results by Domain



*p < .01 versus Physical; p < .05 versus Environmental

Qualitative Results

Ten participants completed the semi-structured interview, with one participant opting out after they had completed the WHOQOL-BREF. The qualitative data were coded and analyzed based on the Interpretive Phenomenological Analysis (IPA) process. The data were then organized into five Group Experiential Themes (GETs): (a) "working the program," (b) dynamics with others and self, (c) "I've been having breakthroughs," (d) meaning, and (e) areas for improvement in the program. Table 4.3 includes the Personal Experiential Themes (PETs), or subthemes identified within each GET, as well as the number of participants who described the GETs and PETs during their semi-structured interviews. Table 4.4 includes specific detail on which GETs each participant described.

Table 4.3

Group Experiential Themes and Personal Experiential Themes (Number of Endorsements)

Group Experiential Themes	Personal Experiential Themes
Compliance: “Working the Program” (10)	Following the Schedule (10) Privileges: “We Get More Leeway” (9) Increasing Demands (10) Tokens as Currency (10) Pleasurable and Relaxing Activities (10)
Relationship Dynamics with Self and Others (10)	Other Clients: Passing Time (4) Staff: “Caring… and Helpful” (7) Providers: Promoting Recovery (7) Frustrations (10) Mood (10)
“I’ve Been Having Breakthroughs” (10)	Increases in Functionality and Coping Skills (10) “Understanding One Another Clearly and Respectfully” (6) Reflection and Acceptance (4) Learning from Life Experiences 5) Medication: “Drugs Keep Me Alive” (7)
Meaning (9)	Belief in a Higher Power (5) Value of Family (7) Sharing Advice (3) Planning for the Future (8)
Areas for Improvement in the Program (10)	“Slow” Process (6) Bathrooms (2) Negative Side Effects (4) Being Restricted (7)

Table 4.4

Participants' Endorsements by Theme

	Participant #									
Theme	1A	2B	3C	4D	5E	6F	78	8F	9I	10J
Compliance: "Working the Program"	X	X	X	X	X	X	X	X	X	X
Dynamics with Others & Self	X	X	X	X	X	X	X	X	X	X
"I've Been Having Breakthroughs"	X	X	X	X	X	X	X	X	X	X
Meaning	X	X	X		X	X	X	X	X	X
Areas for Improvement in the Program	X	X	X	X	X	X	X	X	X	X

Group Experiential Theme 1. Compliance: "Working the Program"

The "Working the program" Group Experiential Theme (GET) contains narratives that demonstrate the participant's responses to questions about core tenets of the Social Learning Program (SLP). "Working" the program is the fundamental intervention described by administrators, staff, and clients that indicates clients are complying with the rules of the SLP. Five Personal Experiential Themes (PETs) emerged to inform this GET: (a) following the schedule, (b) "We get more leeway," (c) increasing demands, (d) tokens as currency, and (e) relaxing and enjoyable activities.

Personal Experiential Theme 1a. Following the Schedule

This Personal Experiential Theme addresses the foundational facets of the SLP, which all participants discussed during their interviews. Their narratives described the multitude of ways they are able to acquire tokens and how they progress to higher levels, all of which specifically include following the SLP schedule. Participant 4D said one needs to "go to activities and work the program" to earn tokens, and Participant 5E added, "We get out of bed about 5:30 or 6. If you get up on time and bed area's good and you take a shower, you get tokens." Participant 2B shared that a person needs to "do the program, go outside, play bingo, play pool, go to every program that you can" to acquire tokens and to get to a higher level. Other participants noted that attending groups are an instrumental part of the schedule. Participant 7G reflected:

> You earn tokens, about at least 10 a day, you have to go to meals, you do your appearance checks, you have to wake up early, you have to attend all groups, all groups, not some, just keep up the good behavior.

Similarly, Participant 8H described having to:

> [F]ollow the schedule. They put a schedule on the window for every day. Monday through Sunday. And you follow it and do everything that they ask you to do, you do it. You get up and go to group and do what they say to, take a shower, do what they say to, continue to do everything you're told. If you do that you'll promote for a higher level. Each week you have a chance to promote to a higher level. Then you make it to Level IV.

Personal Experiential Theme 1b. Privileges: "We Get More Leeway"

As clients progress through the program and obtain higher levels, there are additional privileges afforded to them, like leaving the ward for work (BVE) and leisure. Participants described enjoying the ability to gain tokens and levels, which is different than other living areas or facilities they had been on in the past. Participants described the balance of finding higher levels to be more demanding, but with additional privileges afforded. Participant 11K enjoyed the ability to do "level shopping," which is only available to those on Level II and higher. Many participants described enjoying getting off the living area and doing other activities. After clients achieve the highest level (Level IV), they receive a credit card with tokens and the ability to obtain vacation hours, or hours for excused absences from group, which participants also described as positives of the SLP.

Despite the challenges of maintaining a higher level, several participants described the benefits as well, including Participant 10J, who shared that a higher level allows a person “more leeway,” and Participant 8H shared, “You get to do less work, and they put you on a pedestal a little bit.” Participant 9I illustrated that a person can “go places and stuff, like the library, and go to work make money, that’s what I really like” on Level II or higher. Participant 11K added that a person is able to “[go to] treatment, to go to Canteen and Hope Center, and get a green badge, get to spend some time to yourself in the Hope Center and library, mingle and talk with other people,” because clients from different living areas are able to be in the Hope Center at the same time, as opposed to being a Level I and only getting to interact with other clients on their assigned living area. Participant 5E explained,

> [On] Level III you get more privileges. You get more tokens and stuff like that. You get tokens on Level II too I guess, but more tokens and privileges on Level III. On I you don’t get no privileges; you don’t get to do what you want to when you’re a I.

Several of the participants described the ultimate goal of achieving Level IV, where, as Participant 7G described, clients “get a credit card with 250 tokens” along with “vacation hours,” where clients are able to exchange the vacation hours for an excused absence from group. Participant 6F added that being a Level IV “allow[s] more opportunities to enjoy yourself,” and Participant 5E also explained that on Level IV, a person can:

> [G]et [a] green pass and a credit card, a voucher, about this big, you can fold it up if you want. You get more privileges on Level IV, you get your green pass and can go over to canteen by yourself, without staff. You can go outside. You get to leave the hospital, you know, on Level IV.

Personal Experiential Theme 1c. Increased Responsibility

The participants all shared similar sentiments that all the levels required increasing levels of expectation. Participant 11K shared that:

> Level II is like okay, wake up, reality check time, gotta go to work, whereas Level I is like, you're getting tokens, you have enough to get you through, and you just are keeping to yourself, can be comfortable. Level II you have to challenge yourself. You gotta wake up to a new day. It's like going to school, but you didn't like going to school, so sometimes on Level II you want to play hooky, but then you lose your level. If you don't stick to doing what's required of you and play hooky, then you get dropped [to Level I].

Similarly, Participant 3C shared they "have to go to groups to keep my level" and that they cannot be in their rooms or watching TV if they want to maintain the higher level. Participant 3C also highlighted the increasing demands of being a Level IV and that, "It's easier to be a Level III than IV, you have to work harder." To keep a higher level, Participant 10J described expectations of having "to keep up with housekeeping" and attending "more informals" which are interactions during which the clients and/or staff play games, talk, or participate in unstructured activities together. Participant 6F described staying focused on "groups, BVE, staying out of trouble" when asked how they had maintained their Level IV for over a year, and a few other participants also described planning to continue attending groups to keep their higher level.

Personal Experiential Theme 1d. Tokens as Currency

A fourth Personal Experiential Theme (PET) illustrated the importance of tokens as currency within the Social Learning Program. This PET also highlighted the participants' different approaches to spending and saving their tokens and demonstrated their varied interests, evidenced by the things they described buying. Most of the participants described liking the tokens and their ability to make choices regarding their tokens, with several showing me their physical tokens during the interview.

Participants described needing to use their tokens for most of their day-to-day activities outside of group, including buying time in their room to spend time alone, buying time to watch TV, use a radio, attend movie night, and go in the game room. In addition, participants reported also using tokens to go in the ‘comfort room,’ which was described as being similar to a timeout room or a way for participants to spend time by themselves outside of their own room. In addition to buying time for various activities, a plethora of purchasable items were described by participants, including food, drinks, hygiene items, clothing, shoes, envelopes and stamps, and makeup.

Personal Experiential Theme 1e. Relaxing and Enjoyable Activities

Group attendance and participation are essential requirements of the Social Learning Programs and are the key tasks for clients earning tokens, meeting requirements, and promoting to higher levels. Despite the groups being obligatory, participants described enjoying them as well, indicating that they are a positive of receiving treatment on the SLP. Participant 4D enjoyed the groups because groups keep them “active” on the living area. Two participants explicitly stated enjoying Small Group, where clients work though different problem-solving steps and application to a variety of real-life scenarios. Participant 7G liked the more leisurely groups, including the Music Group, adding,

> [We] get to watch videos, play drums, maracas or something like that. I like that one. Nine o’ clock group be good too, we do trivia with questions… At 4:20 we do other stuff too, like word search, puzzles. I’m pretty good at those.

The participants highlighted their appreciation of the variety of leisure activities that are available to them, including watching movies, going outside, getting popcorn movies, bingo, and playing games with peers and staff. They also described enjoying the ability to go to the Hope Center, shoot pool, use the game room, and go to the library, which has internet access. Participant 5E described and showed me the various printouts of items that they were going to request to buy via their case manager. Participant 11K had specific examples of how they found meaning on the SLP, adding, "I look at US magazines and I find them very fascinating. Look at the stars and what they're doing. Enjoying the scenery and the lights, reading, watching tv, observing my peers (laughs)." In addition, Participant 7G shared the following:

> We go outside when it's nice, on the patio for like 10-15 minutes, listen to the radio. Sometimes we also go out in the courtyard and play ball or volleyball, or something like that. Or just sitting and enjoying the sun… It helps maintain and motivate me. I need the fresh air. It's a good thing about the program.

Many of the participants spontaneously described how much they like having their own rooms and the privacy and solitude afforded to them while they are in their rooms. Participant 5E elaborated by saying, "[P]eople don't bother me in my room… We can have time to ourselves versus being out there with them. I like to have the freedom to be by myself." Participant 6F described being excited to come to the SLP, knowing that they would get their own room on this program.

Group Experiential Theme 2. Relationship Dynamics with Self and Others

This section explored the Group Experiential Theme (GET) regarding various connections with others and their own mood. Because all participants were explicitly asked about their relationships with other clients, their treatment team, and the floor staff, most gave lengthier responses regarding these relationships. While some of them did give spontaneous responses about their interactions with others on the SLP, most required additional prompting to share their experiences regarding interpersonal relationships. In addition, participants were explicitly asked about their mood.

Personal Experiential Theme 2a. Other Clients: Passing Time

All participants described their relationships with other clients on the SLP in their interviews. While the majority of them described positive interactions with their peers, few of them reported any meaningful connections. When asked if they would describe their peers as friends, most said no, and offered explanations that their peers simply help them pass the time, typically by playing cards or by engaging in small talk. Participant 7G offered the following explanation:

> Me and [client name] are good. We play cards together, we eat at the same table. When we go to the fitness program we walk around together. We're okay with each other… I don't want to say connected, but someone to pass the time with. An associate… This is normal for me because we are at a mental hospital and I see a lot of changes in people, personalities and stuff like that.

Conversely, for Participant 8H, they described having only associates and no friends on the SLP, but still shared, "They listen to me and I listen to them, and we share things in common, and it makes it easier to know someone else is going through the same thing you went through."

Personal Experiential Theme 2b. Staff: "Caring… and Helpful"

All participants also described their relationships with the floor staff, or the staff that provide most of the hands-on care on the SLP living areas, including supervising meals and activities of daily living, providing milieu interactions and management, administering medication, completing rounds, and keeping track of behavior on various observation sheets. Participants described their relationships as generally being good with the staff on the SLP, with several describing feeling cared about by staff. In addition, most participants found the staff to be helpful in getting them supplies that they need, that they can talk with staff when they need them, or play cards with them at informal interaction periods. Participant 8H shared that they "are all helpful for the main part, most part." A few participants also commented on feeling connected to staff and that having a good relationship with the floor staff was important to them.

Personal Experiential Theme 2c. Providers: Promoting Recovery

Many of the participants described their treatment team as an integral part of their lives, with their case managers providing connection and services for them. Participant 7G shared their treatment team is "at a 10 on the rating scale; whatever I ask for, they complete it for me, anything I need, anything I need organized, they get right on it." A few participants mentioned their case manager by name and how helpful they are, and Participant 6F shared, "She helps me in groups and everything, social skills. She teaches me the steps. She helps me with my money needs and everything. She is just wonderful." When thinking about their treatment team, Participant 10J shrugged, smiled, and said, "You can learn a lot from people who have control over your life." Participant 5E shared a similar positive sentiment:

> My treatment team helps me too, to show me that I can be not only a better person, but show me I can be somebody too, with the coping and the tokens, shows me how to make a better effort when I get out of here and go to minimum security.

All of the eight participants who mentioned their psychiatrist or other professional who manages their medication stated that they have a good relationship with their prescriber. Participant 7G described being heard and feeling seen in their interactions, adding,

> They did want to take me off my medication but I was like no, I'm good. I don't want to have to start it back over. I said I'm good where my medication is at and will continue to take it.

Participant 7G also described the promotion meetings, where clients find out if they have earned a higher level each week, adding:

> They [case managers] tell you how good you're doing on the program and everything you've done in the last week. They read it out, you got 100% or 60% or something like that [of tasks or groups required for the week] They let you know if you have any reminders or warning. They just let you know how you're doing on the program.

Personal Experiential Theme 2d. Frustrations

Despite predominantly positive statements about their treatment team, several participants noted frustration as well. Participant 8H noted her case manager "changes so much that I have no feeling about them, I don't even know who it is" Participant 3C described "feel[ing] ignored sometimes… It makes me not want to ask for nothing [sic] I need. It makes me feel bad."

Floor staff are fundamental in the lives of clients on the SLP. Several participants described the staff often being too busy to help with requests due to helping other clients, having a poor attitude, and being upset because of tasks not being completed by the other shift. Participants also noted the challenges of being short-staffed, with Participant 2B describing being "locked in our rooms for meals due to being short staffed." Participant 3C shared that the staff are "very cold, they don't give us no love or attention… You have to remind them of everything, remind them to check on your stuff, make sure they write it down, otherwise they will forget." Other participants described feeling like staff try to get them in trouble to get their level dropped. Participant 8H also reflected, "The staff can't even empathize with us. They don't know what it is like having a mental illness, for one. Most of them don't." Poor attitudes from staff were also noted to be areas of improvement, with Participant 11K sharing, "The staff gets rude and don't know what they are doing but you still have to listen to them," and Participant 8H noted:

> Well, they are all helpful for the main part, most part. I'm just saying that sometimes they are impatient and they're angry and they're mad but they're just trying to do their jobs. Or day shift is mad at night shift because they didn't do something and night shift is mad at day shift for not doing it… And when we walk up and say, 'Hey can I have some soap,' 'I'm doing something right now, and I don't know because we are short of staff, I don't know when I can I be with you..' And you're like, 'Damn why does she have to get all snotty, all I'm asking for is some soap and towels.'"

Other participants described feeling that the staff are not on their side and want them to stay in the hospital, so they will do things to get them in trouble or pick on the clients to get them in trouble.

On the SLP, clients spend a considerable amount of time together in groups and in the milieu, especially those that have recently been demoted to Level I or have not obtained Level II yet. At times, clients may frustrate each other, which can lead to tension, hostility, and even aggression. Several participants noted difficult interpersonal interactions at times. Participants 7G, 8H, and 3C spontaneously described feeling frustrated or annoyed with a certain peer on their living area. They described feeling nervous, annoyed, scared, or unsafe due to their peers physically fighting with each other or peers being verbally or physically aggressive to them. These participants expressed frustrated about these peers and described discussing their concerns with staff.

Personal Experiential Theme 2e. Mood

All participants were prompted to share about their recent mood during the interview. Consequently, they all described how they have been doing. I noted that the majority struggled to articulate how they had been doing other than saying they were "fine," "good," "so so," "cool," "average," "moderate," or "medium."

Participant 2B described "always feeling happy" but then shared that the side effects of their medication, resulting in significant tardive dyskinesia, made them sad. Similarly, Participant 6F noted feeling "happy and cheerful" but that the sedating medication effects made them "mad" and were also struggling to stay awake during the interview, which frustrated them. Participant 8H noted their mood has been "good," elaborating, "I haven't been overly excited, running and playing, nothing like that, but I haven't been depressed or overly saddened by anything, where I could just not get out of bed and don't eat."

Participant 7G shared they were a “little worried” about their family but were able to overcome it. Similarly, Participant 11K described bouts of anxiety that they labeled “adrenaline.” They shared, “It puts me in fear… It makes me worried about having a place to live, frightened. I feel embarrassment and pain sometimes too.” Other participants shared they were concerned about what was going on in the outside world, based on what they see on the news.

Participant 9I noted feeling frustrated because someone told them their “leg was going to be chopped off,” which illustrates that despite this information being seemingly irrational or not reality-based, there are real consequences on mood and functioning that can result. Participant 8H also highlighted the hardships of “having a mental illness.” They shared,

> Sometimes it’s [having a mental illness is] happy land and sometimes it’s sad tears…It’s not easy having a mental illness. I still wanna play with my toys. I still wanna slide down the slide… I want to do those things because I’m mentally ill. That’s called mild retardation, you might not know about that. You wanna slide down the slide, you wanna play with the kids, enjoy the equipment at the park… And I have kids so I have to be the grown up, I can’t be a little girl.

Group Experiential Theme 3. Meaning

Participants were explicitly asked in the interview how they find meaning in their lives. As a result, nearly all of them offered perspective on their experiences and what is meaningful to them.

Personal Experiential Theme 3a. Belief in a Higher Power

Several participants described finding meaning through praying to their higher power. Participant 6F described praying they "can get some help," and Participant 7G shared they "pray about my family… [B]e able to cope with this situation too, I pray about, just, good days. Continue to let me have good days." Participant 3C illustrated the importance of religion in finding meaning, sharing that, "[T]he higher power is who we reach out to, to help us… It's important because my salvation is at hand… Well, Jesus says I'm precious… I'm special and he loves me. I have meaning."

Personal Experiential Theme 3b. Value of Family

Seven of the 10 participants described the importance of their families. In addition, they illustrated how some of the meaning they find in their lives can be attributed to the connection they have to their family, with Participant 5E recounting, "My family is everything to me." Many described frequently calling their children, grandchildren, siblings, parents, and extended family members to stay involved and catch up on their day-to-day. This was illustrated in Participant 10J's depiction of the meaningful connection with their family:

> [T]hey are my support factors. They do that for me… I try not to [call my sister] too much (laughs). If I'm calling off the chain then she tell me 'Hey buddy, you need to lay off. She keeps me [inaudible] basically to just keep doing good. She always checks in and asks about my treatment, how I'm doing. She says 'Just do what you gotta do, you'll be alright.'

9I noted how their children "give me a reason to live and to wake up. To work the program," and Participant 7G shared they appreciate their family because they "motivate me. Just to know I have someone to love me, cherish, and to be with them in my life."

Personal Experiential Theme 3c. Sharing Advice

Three of the participants described a sense of meaning and pride in sharing advice with their peers. Participant 3C shared their experience of being a Level IV and:

> Staff will look at you and say 'Yeah, he's a Level IV, he'll give you good advice' cause [sic] I'm a Level IV… They'll say 'Show them the ropes'… It's alright. I help some people… [T]hat's helping them with their program.

Participant 10J described how reflecting on their own experiences makes them want to guide others in their journeys, noting:

> I try to keep it real. When I see a guy who is 10, 12, 15 years younger than me come through here, I try to tell them, 'You've got your whole life ahead of you. Don't make this a habit.'… How can I put this, Ms. Alexa, I always say this over and over, 'You're the master of your own destiny.'

Similarly, Participant 8H specifically described the advice they share with their peers:

> I try to give people inspiration that things will get better. I been on the wet side of the river bank that you've been on, and you're gonna get over to the dry side sooner or later, baby. You have to succumb to what you're doing and look around and look at yourself and say, 'Why am I doing this? What's the problem? If there's a problem let's get rid of it, and stay getting rid of it'… And you give them advice because it's over with for you, and it's still going with them… Even if you're not in their shoes you tell them 'Carry on and go on with your life. Leave the bad parts of it alone and don't worry about these people. Your children are fine, you're working the program, and you have your space.' It's hard.

Personal Experiential Theme 3d. Planning for The Future

Nearly all participants (8/10) illustrated that they find meaning in thinking about and planning for the future. Participant 7G described how thinking about the future “helps me stay focused, listen, just soak a lot of the goodness in.” Participants 11K and 10J noted that they found meaning in thinking about going back to school or getting out of the hospital and finding a job. Participant 9I noted that getting out provides “hope that we can go somewhere.” Participant 3C shared that “something to look forward to” helps them find meaning; they look forward to getting out and having intimacy with a romantic partner. Participant 6F also described looking forward to getting a “green ID and grounds pass” and that these were goals they had set for themselves. Participant 5E also illustrated how their treatment team has helped them plan for the future, noting:

> My treatment team helps me too, to show me that I can be not only a better person, but show me I can be somebody too. The coping and the tokens shows [sic] me how to make a better effort when I get out of here and go to minimum security… I wanna not only keep this in mind with coping and other stuff, I wanna move on with my life.

Group Experiential Theme 4. “I’ve Been Having Breakthroughs”

This section illustrates the breakthroughs and learning that participants described in their interviews. They were all explicitly asked about topics or things they learned while they were on the SLP, and most of them offered comments about the skills that they learned in various groups on the SLP, while others described lessons learned while on the SLP or from more general life experiences. As such, this Group Experiential Theme was made up of five Personal Experiential Themes (PETS): increases in functionality and coping, social skills, learning from life experiences, reflection and acceptance, and “drugs keep me alive.”

Personal Experiential Theme 4a. Increases in Functionality and Coping

Nearly all of the participants reflected about the skills they learned from different groups on the SLP, including consistently completing job, hygiene, cooking, and housekeeping tasks, which they learned Functional Skills ("Function") group, a cooking class, and at their off-living area job at "BVE" (Brandt Vocational Enterprises). Participant 3C noted how much they enjoyed learning, particularly in Small Group, where they apply problem-solving skills to real-life scenarios; they enthusiastically shared they like this class because, "I understand because I know all about it. I know the steps. Identify the problem, solutions and coping skills, pros and cons, test it out." Three participants also mentioned enhancing their math, science, and other basic knowledge, with Participant 7G specifically noting:

> There's one or two classes we do different things, like last time we did math. We counted up to a billion because she wanted to see where we were at. We did multiplication, subtraction, and last time we did a calendar and how many days in a week. So, it's alright… We talked about handling disasters. We also talked about Jupiter and Pluto and stuff like that. That's the big picture stuff.

All participants described a variety of coping skills when feeling upset. They offered the following words and descriptions: "spades," "radio," "talk with family," "take a PRN," "the comfort room," "my room," "TV," "movies," "music," "walk around," "take a nap," "read," "journal," "try to be patient," "talk with my associates." In addition, four participants shared that they use prayer to cope, three offered "working the program" as a coping tactic, and Participant 10J elaborated further about their coping process, sharing:

> I'm good at avoiding trouble. (laughs). Like when I know some shit is gonna kick off, I go in my room, read the paper. They let me don't let me do it, but I wait, take some papers, go in my room, stash them, read my ass off. Keep myself busy.

Personal Experiential Theme 4b. "Understanding One Another Clearly and Respectfully"

Learning and enhancing social skills were also frequently mentioned, with Participant 4D noting the importance of "holding a conversation," and Participant 9I sharing, "you gotta learn how to be social with others when you get out." Participant 3C also described learning about "how to ask for help, having one on one conversation," and Participant 6F described having an "understanding of one another clearly and respectfully," which they learned in social skills group, where clients "play role plays, practice social skills, take sides from one another, pinpoint things that we are dealing with." Regarding social skills, Participant 10J also described learning "how to be more expressive, like how we are talking now. When I have something positive to say, I try to say it in a certain way so I don't get victimized for saying it in some type of way." Participant 7G further illustrated that learning has been key for them, sharing "social, function, and small group" are helpful to "be able to socialize when I'm on the outside, you know, have good communication, attending to important stuff."

Personal Experiential Theme 4c. Learning from Life Experiences

Participants reflected on learning from life experiences and external factors while on the SLP. The importance of lessons learned was apparent in descriptions provided by several participants. These included narratives about how participants have learned to better manage their frustrations with other peers or staff, other than resorting to verbal or physical aggression, with Participant 11K adding, "I know how to ignore it and not retaliate back, walk away, get help," and Participant 8H shared:

> When they say you should ball up, you just wait until they break the fight up. Then you get up and say you okay, you okay [brushing themselves off], you don’t get up swinging and trying to fight back, cause you’re gonna get a demotion just like the person who hit you.

A few participants also shared the learning that has taken place for them on the SLP and how they will apply it to future situations, with Participant 7G illustrating that learning has been important for them because:

> We get to watch the news too… There’s a lot going on… So I’m trying to prepare myself for that. I was in the midst of that but I’ve only been gone for about 4 years, I’m learning. I’m learning. [It’s important to] see that that I’m trying to get to the next level, to participate, to get out. Avoid situations better. It is changing out there and they are preparing me for if you get back out there.

In addition, Participants 11K and 8H had lengthier descriptions of the learning that has taken place, with Participant 11K specifically noting:

> I’ve been having breakthroughs, things I should have learned when I was 10 and 13 years old, I didn’t learn until I was 56. I’m 58 now… Things like, don’t just talk to anybody, you don’t just share your body with anybody. Watch who you talk to, watch what you say. Those are two of the most important things you’ll ever learn in your life. If that person looks bad to you, and you heard a person say demeaning and bad things or behaviors, you don’t associate with them. Then when you like someone, you don’t just go to bed with that person immediately when you met them just because you like them and you’re crazy about them and they made you feel so good, you don’t just hop into bed with them and start kissing them or something.

Additionally, when asked if these were all concepts they had learned while on the SLP, Participant 11K went on to say:

> Oh yeah! Before I came here, people I met, just because I met them. I would want to go to bed with everybody, but I did do it too much. Now I would say I really have to like this person and have to mentally picture being with them, then I might be like ah, okay. Those other times I carried on, I never should have did it. My boundaries are much better now…I want to respect my body and myself. When I think about the [their name] up to about 48 years old, I just shake my head and think to myself, how could I be so stupid? I took an AIDS test recently and I don't have AIDS, and that's amazing because of how careless I was.

Participant 8H described their own learning process, adding the following:

> They're getting us ready to go ahead and get us an apartment in a new environment. Or maybe it's the same environment, but you're a new person. And you can cope, cause you learned how to cope with things. You might see some of your old friends that you don't really want to see and you're speaking to them and they're trying to invite themselves to your house and you really don't want it, man, you gotta be strong. Like, 'Hey look, I'm not going home right now, I'm on my way to [inaudible] but I'll check you guys later.' And then you go.
>
> Set boundaries… You want to drink or something like that, and you know that drinking is going to be bad for you, and it always has been, you always get into a fight with somebody, you always want more to drink, you can't just have one more to drink, you know not to pick it up. Picking it up comes with trouble and you start yourself over again and you're gonna have the same experience. Your family ain't going to be speaking

> to you, your sister is going to be mad at you and keeping you away from her children, the babies are going to be crying and wanting to go with you and they can't go. It's a 0 if you're going on a scale from 0 to 10, you going right back down to 0. I see maybe a little wine, a wine cooler, or something like that, and then forget about it. No! You go and drink a soda, maybe smoke a cigarette or something. You don't even need the cigarette if you took your medicine when you get out the hospital [sic]. You keep on taking it, you don't even need the cigarette.

Personal Experiential Theme 4d. Reflection & Acceptance

Four participants illustrated that they coped with their individual processes by using reflection and acceptance, with Participant 7G noting, "I deal with it the best I can. I brought myself here and I want to get out," and Participant 11K illustrated their level of acceptance in saying "I had a treatment team meeting, and I told them, I want to stay here the rest of my life. That thought still is in my mind now." Participant 11K also reflected on their experience of giving their children up for adoption earlier in their life and the level of acceptance they have with it now, adding,

> In sharing that with you, I don't want to bring them up anymore, but I think it's just a part of my life that happened, that never should have happened… Mostly I rejoice that I didn't keep her or him, I'm happy that I didn't keep them, because I just wasn't myself. I wish the best for them."

In their own descriptions of reflection and acceptance, Participant 10J added:

> I like the whole format [of SLP]. It is only what you make of it. If you come in here and do what you gotta do… Life is not always peaches and cream, you know what I'm

> saying? But you gotta be cool. Find your peace, keep it real. I enjoy life and do what I can.

Relatedly, Participant 8H shared,

> I don't solve problems, I let the problems solve themselves. Your life is what you make it. You want to be a train conductor, do it. if you want to be a nurse, be a nurse. The sky is the limit. You limit your own self. You put stumbling blocks in your own way. You can walk away. You have options and coping skills… If someone throws a bottle at your foot and it breaks and some of the water or soda gets on your foot, you don't have to get 'P'ed off. You can just go, 'Hey man, watch out' and go about your business. Sometimes you cannot change the problem but you can change the environment, you can change the extent of the problem, but you cannot take it away, the problem will still be there. You can cope with the problem, learn how to manipulate it, or you can just sit and say 'it is what it is'. Sometimes you just gotta get on with it, like here's the problem, what happens next? When you try to make things happen you might run into a brick wall and still be trying to make it happen. Sometimes you just need to chill out and wait. You want some rain on your garden? What you gotta do? You gotta wait. You can't make it rain.

Personal Experiential Theme 4e. Medication: "Drugs Keep Me Alive"

The majority of the participants described the positive effects of medications, with two describing that medication helps with anxiety in the moment. Five participants described their appreciation of the effects on a longer-term basis, noting that their current medication regimen was effective for them and they were agreeable to taking the medication. Participant 10J stated the following about the medications, "I take a whole lot of psychotropic drugs you know? If it wasn’t for the drugs I don’t think I would have a life. I don’t think I would be living.” Participant 8H shared a similar sentiment, noting:

> The medication they have me on here is better. If they have me on sugar pills, then I should have been on sugar pills years ago... But if they have me on some type of psych meds that are making me able to get up and function, and I can smile and laugh. I used to be where I couldn’t even smile, and now I can’t cry. My medication is making me stronger, as far as hearing sad things and knowing something bad happened, like I can’t cry. It’s like, ‘you can handle this without tears and napkins and handkerchiefs. You can handle this, be strong. Think positive things’… I love them, every drop of them… It helps me. Years ago, I would have been there in the bed, I’d have been fat, I would have had gunk all over my face, I would have had a little fro sticking out, I would have been feeling a mess and looking a mess.

Group Experiential Theme 5. Areas for Improvement in the Program

Despite many positives of the Social Learning Program (SLP), all participants also shared areas for improvement, or things that negatively impact their experience while on the SLP. This section explores these perspectives and the challenges clients on the SLP experience.

Personal Experiential Theme 5a. “Slow” Process

The resounding response about the process of coming to the SLP was one word, “slow”. Participants were quite aware of the time they have spent in the hospital, with length of time ranging from nine months to 37 years. Those that highlighted their admission length described a common interest of wanting to leave and to go home.

Personal Experiential Theme 5b. Negative Medication Side Effects

The medications used to treat schizophrenia spectrum disorders are typically antipsychotics and mood stabilizers. Although they are effective at treating both positive and negative symptoms of these disorders, the side effects can be difficult for individuals to endure (Ricciardi et al., 2019). Participants here illustrated the difficulties of managing side effects; Participant 2B demonstrated the towel they use due to tardive dyskinesia that causes significant facial tics, which, in turn, cause drooling. They added:

> I take my meds. My meds are hard. They make my mouth like this and I have to use a towel. I drool when I eat and I have to use a big towel… It makes me sad. Makes it hard for me. Makes it hard to eat, I have to use the towel all the time, it messes my clothes up.

Participant 11K described significant joint pain that has resulted from years of chronic usage of mood stabilizers. Participant 6F's symptoms during the interview illustrated the sometimes-sedating effects of antipsychotics; they noted feeling agitated because they were trying to concentrate and listen to me during the interview but were simultaneously nodding off. They went on to say that they always feel very tired in the morning and usually take a nap shortly after their medications are administered.

Personal Experiential Theme 5c. Being Restricted

Generally, there are many constraints on what clients receiving treatment in a forensic state hospital are able to do. This is particularly true on the SLP, as it is housed in a high-security facility. Participants described feeling restricted in what they are able to do, noting that the SLP is stricter than other programs, both at Fulton State Hospital and in other facilities they have been admitted to. Participant 2B noted that when they were on a different program, they were able to smoke cigarettes and go to Canteen with more leniency. Participant 4D described frustration that they are not able to be intimate with other people because of hospital policy, and Participant 11K shared discontent about staff setting rules about what they can or cannot have in their room. In addition, Participant 3C felt restricted by having to constantly “pay, pay, pay” for everything, and Participant 8H noted having “no respect for this program” because of having to start over on Level I if “someone hits you and you hit that back.” They disliked the rigidity of the rules surrounding verbal and physical aggression, particularly if they perceived it as self-defense.

Clients on the SLP have a full schedule every day that begins early and goes throughout most of the day. Unless they are willing to spend their tokens to do other activities, they are generally limited to following the SLP schedule. Their routine includes completion of various hygiene and housekeeping tasks, groups, and participating in meetings with their treatment team members. For those who have obtained Level II and higher, there are also opportunities to leave the living area and go to work or participate in other leisure activities. The participants described wishing there were more opportunities to spend time alone, with Participant 7G shared they would like more “time in our rooms, spend time by ourselves to recuperate and just get more rest... Just a little more time, not too much. We do activities from 9 o’clock to 6:15.” Similarly, Participant 4D shared, “They want you just doing group and group and group,” and Participant 3C noted wishing they did not have to do groups “all the time” or on the weekends.

CHAPTER V: DISCUSSION AND LIMITATIONS

The purpose of this study was to gain perspectives on the QoL of individuals with diagnoses of schizophrenia spectrum disorders residing and receiving treatment on the Social Learning Program (SLP) of Fulton State Hospital. All 11 participants described their perceptions of their own QoL through the use of the WHOQOL-BREF. The items of the WHOQOL-BREF are rated on a 5-point Likert scale, either from "very dissatisfied" to "very satisfied," "very poor" to "very good," or "not at all" to "completely," depending on the question posed. In addition to the completion of the WHOQOL-BREF, 10 participants completed a semi-structured interview and described their lived experiences and QoL. In accordance with the convergent parallel mixed methods design, data integration was accomplished by merging the data "(i.e., combining and comparing/contrasting the results of interviews and surveys that were collected/analyzed separately)" (DeCuir-Gunby & Schutz, 2017, p. 119).

This chapter begins with integration and interpretations of the study findings, including triangulation between the quantitative and qualitative results in the context of theory and prior research. Positive impacts of the SLP and areas for SLP improvement are detailed. A general discussion regarding the future of SLP is provided. Study implications are followed by limitations and directions for future research. This chapter ends with study conclusions.

Integration of Quantitative and Qualitative Results

Goals of SLP

The SLP was created in the late 1970s, with the overarching basic goals of increasing prosocial behavior and decreasing aggressive behavior (Paul & Lentz, 1977) in inpatient populations with lived experience of serious mental illness (SMI). The SLP is considered a best practice for inpatient treatment by the American Psychological Association (2007). The SLP has become an effective treatment program for many individuals with SMI who experience profound functional deficits and have had lasting symptoms or difficulty with reintegrating with the community. Because of its efficacy, the SLP was implemented in the 1990s at Fulton State Hospital, a high-security state hospital. The present study makes a unique contribution to the literature by providing an opportunity for individuals hospitalized with diagnoses of schizophrenia and schizoaffective disorder to share their experience with the SLP and how it impacted their QoL. Further, participants had the opportunity to describe what aspects of the SLP were working for them and what aspects could be improved.

General Impressions of the SLP

Based on what was shared through WHOQOL-BREF responses and the semi-structured interviews with participants, it appears that the SLP is accomplishing what it was designed to accomplish, such as described improvement to functional and interpersonal functioning, and increases of adaptive behavior. In addition, the qualitative responses from participants suggest the SLP provides clients with a plethora of opportunities to earn tokens to purchase desirable items and to participate in pleasurable and relaxing activities, further reinforcing positive, prosocial behaviors.

Overall Quality of Life and the SLP

The overall WHOQOL-BREF QoL score is composed of two items: “How would you rate your quality of life?” and “How satisfied are you with your physical health?” The overall composite score averaged above the scale midpoint in the present study, and above the “good - poor” threshold of Silva et al. (2014), consistent with prior research investigating QoL in forensic inpatient populations (Vorstenbosch & Castelletti, 2020). Further, 8 of 11 study participants scored above the “good-poor” threshold of Silva et al. (2014) for overall QoL.

The reasons for these findings are unclear. Kasckow and colleagues (2001) found that health-related QoL was significantly lower in people diagnosed with schizophrenia in inpatient setting than in outpatient settings, with participants matched in age, education, sex, race, and number of Axis-III physical illnesses. While it is possible that the relatively high QoL scores in the present study were due to the SLP, it is important to note that QoL may be related to time in an inpatient facility. That is, prior research suggests that, the longer a client with serious mental illness (SMI) is hospitalized in a forensic state hospital, the more positively they rate their QoL (Büsselman et al., 2021). The participants in the present study averaged 10 years in a forensic state hospital, while Kasckow and colleagues (2001) did not directly report the time in an inpatient facility for their sample, with the screening criteria defined only as a minimum of six months, with no analyses regarding the relationship between health-related QoL and length of stay. It is therefore possible that time in the forensic state hospital may have influenced present QoL findings.

However, it is important to note QoL varied among present study participants, regardless of admission length. For example, 4D had the longest admission among study participants, but the third lowest overall QoL. Prior research (Büsselman et al., 2021) also suggests that clients who have longer admission may have more acceptance about their situation, but in the present study, those who described acceptance at length in their semi-structured interviews (8H, 10J, and 11K) did not generally report higher WHOQOL-BREF QoL than other study participants. Further, van Nieuwenhuizen and Nijman (2009) indicated that, on average, clients with diagnosed personality disorders report low QoL, but this was also not seen in the present sample of individuals with diagnoses of schizophrenia spectrum disorders, where 8 of 11 participants scored above the “good-poor” threshold of Silva et al. (2014) for overall QoL. There were no significant differences in overall QoL between the four participants who had a co-morbid diagnosis of a personality disorder and the remaining seven participants who did not.

Results of the present study differed from Tong Chien and colleagues (2020) in that participants had the highest overall scores in the Psychological and Social domains, whereas Tong Chien et al. (2020) found the opposite. However, present study findings are consistent with Bergöfer and colleagues (2020), who found that patients with schizophrenia had the highest QoL among groups in their study, including those with anxiety, depression, alcohol addiction, and neurodegenerative disorders. For these reasons, it is not possible to conclude that the relatively high Overall QoL scores found in the present study are directly due to the SLP.

The following sections provide an integrated discussion of present quantitative and qualitative findings regarding psychological, physical, social, and environmental QoL in the context of literature and theory.

Psychological Quality of Life and the SLP

The Psychological domain of the WHOQOL-BREF is comprised of questions regarding enjoyment of life, meaning in life, cognitive functioning, self-esteem, self-satisfaction, and mood. The Psychological domain score in the present study averaged highest of all WHOQOL-BREF domains and was significantly higher than physical and environmental domains. This may appear paradoxical, as study participants each had diagnoses of schizophrenia spectrum disorders with severe functional and skill-based deficits. However, individual items on the WHOQOL-BREF indicated that most participants reported enjoying their lives, are able to accept their bodily appearance, and are satisfied with themselves. Most (9 of 11) participants indicated that they “Never” or “Seldom” experience negative feelings, such as anxiety and depression. While still above the scale mid-point, the lowest scores in the WHOQOL-BREF

Psychological domain were related to participants' ability to concentrate, which is perhaps unsurprising for a sample with diagnoses of schizophrenia spectrum disorders.

Regarding the high WHOQOL-BREF scores within the Psychological domain, it is important to note that 57–98% of people diagnosed with schizophrenia have anosognosia, which can make metacognition, insight, and self-awareness challenging (Buckley et al., 2007; Lehrer & Lorenz, 2014). These factors could have played a role in the participant responses and Psychological domain scores. However, high WHOQOL-BREF Psychological domain scores could also be explained by the participants genuinely having a more positive outlook and lowered levels of psychological distress, for any of a variety of reasons, including participating in treatment on the SLP. For example, adherence to medication may have had a positive impact on psychological QoL. While some participants had difficulty describing their mood, others described their mood as "always feeling happy" or similar (2B and 6F), which may be in part attributable to adherence to medication protocols. The majority of study participants endorse the positive impact of their medications. As 8H stated, "My medication is making me stronger."

Interview responses suggest that high WHOQOL-BREF Psychological domain scores might also be due to belief in a higher power, sharing advice with others, and the value of family. In addition, on the WHOQOL-BREF, 9 of the 11 participants stated they find their life to be meaningful "very much" or "an extreme amount." "Meaning" was a Group Experiential Theme derived from the qualitative interviews, discussed by 9 of 10 participants. Additionally, interview responses support the structured environment of the SLP. Participant liked the structure of the token economy, the ability to earn "leeway" and privileges, and how the increasing demands of the higher SLP levels keeps them accountable and goal focused. As participant 11K stated, "you want to play hooky, but then you lose your level." This accountability fosters the esteem of accomplishment. Participants enjoyed having breakthroughs in functionality and coping skills, further supporting the SLP. Lastly, the Psychological domain scores in the present study averaged higher than previous research on individuals with schizophrenia (Dong et al., 2019), again suggesting that receiving treatment on the SLP is a mitigating factor for psychological distress in this population.

Social Quality of Life and the SLP

The Social domain of the WHOQOL-BREF includes items that assess satisfaction with personal relationships, sex life, and support from friends. Participant WHOQOL-BREF Social domain scores averaged about the scale midpoint but marginally below WHO normative values, consistent with other studies of forensic psychiatric hospital patients (Bouman & Bulton, 2009; Vorstenbosch et al., 2014). On average, clients rated all three areas (satisfaction with personal relationships, sex life, support from friends) above the scale midpoint. They rated their sex lives as the least satisfactory of the three items. This finding could be due to hospital guidelines on sex between clients, but could also be due to social and relational difficulties that are often seen in schizophrenia spectrum disorders.

In the interviews, participants described indifference towards social relationships with their fellow SLP peers. Some called their peers “acquaintances” and shared that they did not view peers as their friends. Rather, participants described playing cards, talking, and interacting with peers as a way of “passing time.” A few participants described the enjoyment they experienced from sharing advice or relating their experiences with their peers. Conversely, participants regarded interactions with staff and treatment providers to be more meaningful for them, describing them as being caring, helpful, and “wonderful.” Frustrations were noted regarding poor staff attitudes, not having needs met when the staff was busy, and the frequency of changing case managers. Fear and anxiety regarding unpredictable or aggressive peers were also noted by the participants. Combined, present findings suggest that peer relationships may not be crucial for QoL. Present findings also suggest that positive staff/client relationships play an important role in the well-being of forensic inpatient populations, consistent with prior research (Boevink et al.,1995; Coid, 1993; Mason, 1999; Oliver et al., 1996; Tong Chien et al., 2020; Vorstenbosch et al., 2014).

Physical Health Quality of Life and the SLP

The Physical Health domain of the WHOQOL-BREF is comprised of items that examine experiences of physical pain, energy levels, sleep, and mobility, as well as capacity to complete activities of daily living and to work. In addition, one item asks how much medical care a respondents perceive themselves to need on a daily basis. Physical Health domain scores were above the scale midpoint, but lowest among WHOQOL-BREF domains and significantly lower than WHO normative values. These results are perhaps unsurprising, given that 10 of 11 participants were being treated for two or more medical conditions at the time of the present study. The low Physical Health domain scores in this sample may be attributed to a variety of factors, but all participants were middle aged (range: 41-65) and the literature indicates poor physical health outcomes for individuals diagnosed with schizophrenia spectrum disorders as they age (Connolly & Kelly, 2005; McNamee et al., 2013; Pries et al., 2020; Viron & Stern, 2010). The Physical Health domain scores were low despite having on-site, 24-hour medical care available to clients on the SLP. Medical conditions are likely addressed and treated adequately, which would presumably reduce physical complaints and distress.

While the interviews did not include comprehensive discussions about physical health, all participants were asked if they have any concerns about their physical health or ability to complete tasks due to physical limitations. They all answered “no.” Some spontaneous answers regarding physical health came up at other points in the interviews, but were primarily related to side effects of medications. Interestingly, Participant 2B reported the lowest Physical Health QoL and the lowest overall QoL. This participant also provided the most in-depth explanations of physical complaints during the interview, most of which were related to significant tardive dyskinesia.

Environmental Quality of Life and the SLP

WHOQOL-BREF Environmental domain scores averaged above the scale midpoint but significantly lower than WHO normative values. The Environmental scale items address a wide variety of aspects relevant to participant lives on the SLP, including safety, home life, access to finances, services, and functional information, leisure, satisfaction with environment, and transportation. On the WHQOL-BREF, the participants averaged highest on individual items examining satisfaction with access to transport, finances, and health services, and lowest on “How safe do you feel in your daily life?”. Some participants also highlighted fear and anxiety about safety in their interviews as well. However, participants described many aspects that they enjoy about their physical environment, particularly the freedom and privacy of having their own rooms. Participants also described enjoying various leisure and group activities. Two female participants described dissatisfaction with co-ed bathrooms and others described interest in increased access to areas off their SLP living area.

Environmental satisfaction has not been well-researched within forensic inpatient populations. Vorstenbosch and Castellitti (2020) found that forensic psychiatric inpatients were generally dissatisfied by their physical environment. However, it is important to note that the sample of Vorstenbosch and Castellitti (2020) averaged 12 years younger than the present sample, with less than half the time in a forensic hospital. It is therefore possible that longer stays may foster adaptation to the forensic hospital environment (Büsselman et al., 2021). It is also possible that the forensic hospitals in the two studies differed in environmental conditions. Additionally, Fulton State Hospital was recently rebuilt and opened in 2019, significantly improving the living conditions of their clients. Importantly, Vorstenbosch and Castellitti (2020) found that positive views regarding environmental QoL were related to positive daily contacts with staff, consistent with present findings indicating that having good relationships with staff was important to study participants. This finding also aligns with the SLP's emphasis on positive reinforcement of prosocial behaviors, including effective and respectful communication and interpersonal relationships.

Positive Impacts of SLP

Participants were able to sufficiently describe the details of "working the program," including what is required for them to earn tokens and higher levels, how privileges and demands increase as they progress in the program, and how they are able to use the tokens as currency. In addition, they voiced how they have "had breakthroughs," including learning functional, social, and coping skills through the various groups that are required. Although there were significant barriers to exploring their metacognitive processes, there was a remarkable amount of learning from life experiences described by most participants as well. While it is not possible to conclude that their gains are solely caused by receiving treatment on the SLP, it may be reasonable to assume that being in a safe and structured environment allows clients the opportunity to reflect on past experiences, work through trauma, and think about how they existed in the world prior to coming to the hospital.

All participants reported enjoying activities that take place off of the living area, and many of them shared that is a primary reason they want or enjoy being Level II or higher. Research from a Dutch study (Schel et al., 2015) indicated participants had significant dissatisfaction with their inability to leave their living area, whether perceived or factually based, as this was a study of a forensic population as well. This suggests that increased autonomy and control in getting off the living area and participating in new activities (e.g., working, going to other areas of the hospital) are important factors for QoL.

A majority of clients voiced satisfaction with the SLP, and shared that, even if they could change some things, they would not. Specifically, they noted satisfaction in their relationships with treatment providers, feeling cared for by staff, and enjoying leisure activities, various aspects of groups, and having the ability to go off the living area and having increased access to other areas of the hospital. Many participants spontaneously described how much they enjoy the privacy and freedom of having their own rooms and the ability to get away from their peers by going to their rooms. Interestingly, nearly all of the participants reported feeling disconnected or just "passing time" with their fellow peers. Vorstenbosch and colleagues (2014) also noted the importance of client and staff relationships and QoL in a forensic inpatient population. However, Vorstenbosch and colleagues (2014) found that higher reported QoL was not strongly correlated with social relationships in general. Despite lack of concern regarding their peer relationships, some of the participants described liking the social events, including informal gatherings like playing cards or more formal events like bingo and watching movies.

Areas for SLP Improvement

The most important areas for SLP improvement may be to increase the staff size and to reduce negative interactions with staff. Several participants highlighted issues with staffing and that the hospital was frequently short of staff. Staffing in psychiatric facilities has been a national issue, particularly since the start of the pandemic (Miller, 2021). Additionally, the Emergency Care Research Institute (ECRI; 2022) noted that staffing shortages were the number one concern from their annual *Patient Safety Concerns* survey, which examined client perspectives, current literature, and patient safety events. Staffing issues have great impacts on all people involved in this system, particularly the clients. The SLP might therefore be improved by hiring more staff members and training the staff to foster positive interactions and avoid negative interactions.

The Physical Health domain scores were the lowest among the WHOQOL-BREF domains. It is therefore possible that the SLP can be improved by focusing on the physical domain. This might include an emphasis on a heathy diet, and beyond recreational activities, exercise that is specific to improving the health, fitness, and mobility of the schizophrenia and schizoaffective disorder clients at the Fulton State Hospital.

The SLP might be improved by increasing patient contact with the outside world. Interviews revealed that study participants drew strength and meaning from family members and some emphasized their enjoyment from activities that take place off of the living area. It is possible that family visits would increase Psychological QoL. It is also possible that field trips and other novel off-the-living area activities might increase both Psychological QoL and Social QoL.

The Environmental domain QoL scores were significantly lower than the WHO (1997) normative values. To increase Environmental QoL, the SLP might be improved by addressing the living space. Some participants noted that they wanted more alone time in their rooms and nearly all participants described their frustrations with what items they cannot have in their rooms or what they are not allowed to do in this personal milieu. It is possible that the SLP token system can be adjusted to allow clients to earn additional alone time or items to have in their rooms. However, providers from Fulton State Hospital noted they have anecdotally observed that clients have increased engagement in their psychotic processes when they spend excessive time in their rooms. Additionally, the two female participants reported dissatisfaction in having to share bathrooms with their male peers. Members of the treatment teams at Fulton State were previously made aware of this feedback and, after careful consideration, chose not to make changes in attempts to promote gender inclusivity.

While not specific to the Social Learning Program (SLP), there were other things that negatively impacted participants. The primary complaint was related to the length of time spent in the hospital (mean length of admission was ~10 years). Since Fulton State Hospital is a high-security forensic facility and is at the crossroads of the mental health and legal systems, it is unsurprising that the process has been lengthy for these participants. However, it is important to note the challenges this presents for clients in their daily lives, including a perceived lack of autonomy and control. In addition, while participants were generally appreciative of the effects of their medication, the negative side effects were notable for some. The literature contains a plethora of information regarding the challenges of prescribing medication for this population, particularly considering the medical complexities that are often also present (Donald & Stajduhar, 2019). In addition, tardive dyskinesia and other physical health conditions often result from long-term use of anti-psychotics and mood stabilizers (Ricciardi et al., 2019). Considering the age of the study sample (mean = 54 years), it is reasonable to deduce that these individuals have been on medications for several years or even decades, causing further complications.

Implications

The first implication of this study is that valuable data can be directly acquired from inpatient samples of individuals with diagnoses of schizophrenia spectrum disorders. Despite the challenges of working with these individuals, including significant communication issues and disorganized thought, thick, rich descriptions can be acquired regarding their views, their experiences, and their QoL. While patience is required and standardized structured interview items may need to be adapted to draw out responses, the present study highlights the potential value of research methods towards improving the QoL for these individuals. It is hoped that the success of the present investigation will inspire others to boldly explore ways to improve the lives of these understudied and often forgotten individuals by directly soliciting their views, perceptions, and preferences.

The second implication of this study is that the SLP may improve the QoL for clients with lived experience of schizophrenia and schizoaffective disorder. Participants described the positive effects of SLP on their QoL, including increases in functional and social skills, and the ability to enhance their autonomy and control by gaining tokens and higher levels.

The third implication of this study is that the SLP should be expanded. Directors of facilities should be aware of the SLP and its strengths. The SLP has long been recognized as a best practice by the American Psychological Association (2007) for those with the most severe behavioral problems and skills deficits. The results of the present study further support the SLP's implementation on inpatient units. Paul and Lentz's original objective in 1977 was to create a treatment modality ensuring that anyone, regardless of psychological functioning, can learn new skills and modify behavior in positive ways (Menditto, 2002). Prior empirical research and present results suggest that the SLP could be utilized in any long-term treatment facility tailored to treating those with mental illness, regardless of severity.

The fourth implication of this study is the importance of staff in SLP implementation. The SLP is a comprehensive and dynamic program with many requirements, including observation and documentation of client behaviors, groups, activities for clients off the living area, and case management. As such, staff is central to ensuring that the SLP is implemented as intended. As noted by Staggs (2019), there were shortages of nursing staff in psychiatric facilities for over a decade, shortages that were then compounded by the COVID-19 pandemic, and staffing shortages appear to have lasting effects (Miller, 2021). While I was at Fulton State Hospital (FSH) collecting data, I noted that there was a staff bulletin indicating 450 open positions at the hospital. While not all of these positions are nursing or direct care positions, this observation highlights the profound shortage of staff. Staffing issues are compounded by the stress of working in a forensic inpatient facility (Newman et al., 2019). Importantly, study participants indicated that the staff was helpful, but that staff shortages impaired SLP implementation. The implication here is that policymakers and others with political influence should act effectively to ensure that SLP is properly staffed towards ensuring that the promises of SLP can be fully realized in improving the lives of those suffering from severe behavioral problems and skills deficits.

General Discussion: The Future of SLP

While the SLP can confer great benefit, the future of the SLP is in doubt. Dr. Gordon Paul, of Paul and Lentz's original study on the SLP, passed away in 2014. In a briefing about Paul by Mariotto and Davison (2014), they noted the unprecedented scope and depth of that study and Dr. Paul's disappointment regarding the lack of implementation of the SLP in the years that followed, despite the overwhelming evidence that the SLP was a highly effective treatment for those with serious mental illness (SMI). The stagnation in enhancing treatment and rehabilitation of those with SMI has continued into the present day and has the potential to continue into the future as well. For example, Reddy and colleagues (2010) found that, while most doctoral clinical psychology programs have opportunities to seek out practicum experiences in SMI, students are frequently disinterested and there is a scarcity in early career psychologists who specialize in SMI. In addition, Reddy et al. (2010) indicated that many programs do not have specialized coursework on SMI or interventions for treating individuals with SMI. Rather, these classes are frequently geared toward psychopharmological treatment, further limiting opportunity for students to explore and understand psychosocial treatment for SMI. Enhancing coursework, facilitating discussion about the SLP and other best practices for individuals with SMI, increasing awareness of careers in SMI in clinical psychology programs, and creating research groups on SMI, as well as improving and creating funding sources for research are all needed steps towards facilitating growth in this area of our field.

For the SLP to grow and thrive, it is most vital for the community of SLP practitioners to disseminate their data. From a personal perspective, I have many colleagues in the clinical psychology community who have never heard of the SLP, but are highly interested and enthusiastically supportive once they learn that the SLP exists. When they want to learn more, they are disappointed to find that robust SLP data are not readily available. Part of the problem is that the SLP community infrequently publishes their findings and rarely presents findings at conferences. Facilities that employ the SLP, like Fulton State Hospital, where the present study was conducted, are awash in data, as they rigorously and professionally track each client. These data are collected with the focus on the progress of the individual patient, which is proper and rightful, but these data are infrequently compiled toward dissemination for the general public or for the clinical psychology community.

In addition to dissemination of prospective studies, like the present study, the SLP can only grow and thrive if facilities that employ the SLP compile their findings in the form of hypothesis-driven retrospective investigations and share these results at conferences and through publications in peer-reviewed journals. It is also essential that professionals conduct and disseminate their findings using carefully controlled experimental designs, with appropriate control/comparison groups, so that the efficacy of different aspects of the SLP and variations of the SLP can be objectively evaluated by the clinical and scientific communities. Without these retrospective and prospective studies and wide distribution of the knowledge, the SLP community will continue to labor in silence and the future of the SLP is dubious. Lastly, it is possible that formally establishing a national SLP organization would prove fruitful, so that SLP practitioners and theoreticians can work together to promote and optimize the SLP approach, all towards improving the QoL of individuals with SMI, like schizophrenia spectrum disorders.

Limitations

The present study was limited by the sample, which was modest in size and only included residents of a single high-security forensic state hospital with diagnoses of schizophrenia spectrum disorders. The study sample was largely middle-aged Black individuals who did not complete high school. These characteristics may not be fully representative of those in forensic hospitals with diagnoses of schizophrenia spectrum disorders. For these reasons, present findings should only be generalized with appropriate caution.

The present study was limited by the measures, which were self-report quantitative scales and interview responses from people with schizophrenia spectrum disorders, with no objective data or third-party reports to triangulate with patient responses. Further, there was some question about the level of comprehension by some study participants. For example, the WHOQOL-BREF manual specifies that the questions can be read aloud if needed, so if a participant they told me they could read and then completed the questionnaire, their responses were accepted as valid. However, it is unclear if they fully understood the questions or how it applied to them, particularly given that participants had diagnoses of schizophrenia spectrum disorders and they generally had low levels of education. Additionally, while some interview responses were clear, on-point, and insightful, other interview responses were disjointed or incomprehensible. The present study did not measure symptom severity, which is important because the SLP might have differential effects across the spectrum of schizophrenia spectrum disorders.

The present study used a modified approach to Interpretive Phenomenological Analysis (IPA), with more leading questions overall and fewer open-ended questions than would be typical in IPA. These modifications were necessary due to communication difficulties typical to a population with serious mental illness. Most information was collected using standard questions asked of all participants (e.g., mood, relationships, tokens and levels, things they like and dislike about the program), but some items were skipped because the participant was not coherently responding. Lastly, some information was missing from the interview transcriptions, despite best efforts and an additional review of the recordings by a colleague, because it was simply not possible to ascertain what was being said, due to latency of speech, mumbling or muffled speech, wearing masks, loose associations, tangentiality, and responding to unseen others.

The present study was limited by the design, which was cross-sectional in nature, with no repeated or pre-post-SLP observations, no control or comparison group, and no long-term follow-up. It is therefore unclear how stable these findings might be across time. To highlight this point, some study participants changed their minds regarding participation multiple times within the four-day data collection period. This suggests that some responses could have been entirely different depending on mood and level of engagement. It is therefore not possible to robustly conclude whether responses reflected stable views on the SLP or merely views based on the immediate situational outlook of a participant, whether during interviews or on the WHOQOL-BREF.

Future Research

The present study should be replicated with larger, more diverse samples at multiple institutions. It is vital to include samples with demography that matches the population of interest, as the present sample was over-represented in high school educated, middle-age, and Black participants. With sufficiently large and diverse samples, it may be possible to effectively conduct sub-group analyses between demographic groups and across the spectrum of schizophrenia spectrum disorder severity.

Using multiple measures of constructs and additional sources of data, such as objective data, peer reports, family reports, and reports from staff, would be of great value in determining the impact of the SLP on QoL. Questionnaires other than the WHOQOL-BREF that are better suited for the present population should also be considered, such as those geared toward evaluating recovery or more general outcomes for individuals with serious mental illness (Campbell-Orde et al., 2005). Norming the Forensic Inpatient Quality of Life Questionnaire (FQL; Vorstenbosch et al., 2014) for a United States-based sample would be highly valuable.

It may prove fruitful to conduct retrospective analyses of previously collected data to better understand the impact of the SLP over time. Fulton State Hospital’s administration (primarily Dr. Tony Menditto) has conducted extensive research on the SLP and has observational staff and case managers complete incredibly thorough documentation of various client behaviors via their Time-Sample Behavioral Checklist (TSCB) and Staff-Resident Interaction Chronograph (SRIC). Since there is already so much information collected on clients, it may be useful to also track mood by using a brief screener, or examining clients' perceived QoL throughout their admission. This could more effectively gauge clients' internal processes and address these in groups and therapy.

To definitively determine the impact of the SLP, it is crucial to employ prospective experimental designs, with random assignment to treatment and control or comparison groups, using pre-post and systematic SLP treatment assessments over time. It is also important to incorporate long-term follow-up to determine how the SLP intervention might impact the lives of those with diagnoses of schizophrenia spectrum disorders.

Conclusion

The present study of 11 individuals with diagnoses of schizophrenia spectrum disorders residing and receiving Social Learning Program (SLP) treatment in a high-security hospital found that the SLP can confer QoL benefits, including those of a psychological, social, environmental, and physical nature. These findings highlight the benefit of utilizing the SLP and the importance of studying methods to improve the lives of those with lived experience of schizophrenia spectrum disorders.

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APPENDIX A

RECRUITMENT EMAIL TO GUARDIANS

Hello, my name is Alexa Hutzenbiler. I am a doctoral student in Clinical Psychology at Antioch University Seattle. As part of my degree, I will complete a doctoral research project. I am interested in learning about people who are receiving treatment on the Social Learning Program (SLP) at Fulton State Hospital. I would like to talk to them about their lived experiences and quality of life. I am reaching out because your ward is on the SLP.

I would humbly ask you to consent to having your ward participate in this research. If both of you agree, your ward would complete one survey with 26 questions related to quality of life. They may also be invited to complete an interview with me. In this interview, they would be asked about their lived experiences and their quality of life. These interviews could last between thirty minutes and one hour. I would also collect some basic details about them from their hospital record.

One benefit of this study could be gaining an understanding of people's lived experiences while receiving treatment on the SLP. Doing research on the SLP can help us see how this program affects quality of life. Studying both of these aspects can help us better serve these people as well as those with similar needs.

They will receive $5 if they complete just the survey or $15 total if they complete the survey and the interview to repay them for their time.

Thank you for your consideration. If you have any questions, comments, or concerns, please contact me at XXX.

Best,

Alexa

APPENDIX B

RECRUITMENT LETTER TO POTENTIAL PARTICIPANTS

Hello, my name is Alexa Hutzenbiler. I am a doctoral student in Clinical Psychology at Antioch University Seattle. As part of my degree, I will complete a doctoral research project. I am interested in learning more about people who are receiving treatment on the Social Learning Program (SLP) at Fulton State Hospital. I would like to talk to you about your lived experiences and quality of life because you are receiving treatment on the SLP.

Please think about participating in my research project. If you say yes, you will complete one survey with 26 questions about your quality of life. You may also be invited to do an interview with me. In this interview, you would be asked about your experiences on this ward and about quality of life. These interviews could last between thirty minutes and one hour. I would also collect some basic details about you from your hospital record.

Doing research on the SLP can help us see how this program affects quality of life. Hearing about lived experiences can help us understand how things are going for you and for other people who are on the SLP. These aspects can help us better serve you and other people who have similar needs.

You will receive $5 if you complete just the survey or $15 total if you complete the survey and the interview to repay you for your time.

Thank you for your time! If you have any questions, comments, or concerns, please let me know.

Best,

Alexa

APPENDIX C

CONSENT TO PARTICIPATE IN RESEARCH - GUARDIAN CONSENT

Purpose, duration, procedures

Your ward is invited to participate in a research study. The purpose is to study quality of life of people who reside and receive treatment on The Social Learning Program (SLP) of Fulton State Hospital (FSH). I also seek to understand their lived experiences and how they have made sense of the quality of their lives.

If you both agree, I will collect basic details about them from their hospital records. This will include age, gender identity, race/ethnicity, and level of education. It will also include mental and physical health diagnoses, admissions to FSH, length of current stay, date of admission to the SLP, guardianship status, and civil/forensic status.

They will be asked to complete the WHOQOL-BREF. This is a survey with 26 questions. The WHOQOL-BREF has four domains related to quality of life. It also includes one facet covering overall quality of life and general health. These questions will require about 20 minutes, depending on the person's reading ability. I can read the questions aloud if needed.

A few people will be asked to do an interview with me. This will include questions about receiving treatment on the SLP. There will be questions about their quality of life. I will ask about how they have made sense of the quality of their lives. The interview could take between thirty minutes and one hour. Interviews will be audio recorded.

Participants will receive $5 for just the survey or $15 for completing the survey and the interview.

Participant rights

This process is voluntary. You and they have the right to decline or withdraw from the research at any time without penalty. Even if you consent, they will also receive a separate informed consent.

Participation consequences and benefits

These discussions can be distressing. If at any time you or they wish to stop, please let me know. I will discuss using their treatment team for support if they are having a hard time. I will also include handouts about the stress recovery model.

One benefit of this study could be gaining a better understanding of people's lived experiences while receiving treatment on the SLP. Doing research on the SLP can help us see how this program affects quality of life. Studying both of these aspects can help us better serve them as well as those with similar needs. Another benefit is the small monetary incentive.

Limits of confidentiality

All details provided will be treated confidentially. I will ask participants to avoid using their own name or the names of others in the recorded interview. Surveys will be de-identified and stored in a locked file cabinet. All recorded data from the interview will be encrypted and kept on my password protected computer. These will be stored for later analysis. Audio recordings will be deleted no more than one year following the interview. There are risks with digitally stored data. All participants will be informed in the unlikely event of a breach.

Research results will be anonymously reported. Some quotes from the interviews may be used in the final report. However, I will include the least amount of detail possible. This informed consent will be the only piece of identifying information and will not be linked to any other materials for the study. The informed consent will be stored in a locked file cabinet.

Clients on the SLP have a treatment team who provides care and assists with their treatment. There are also polices in place that provide guidance if a client has thoughts of or intention to commit self-harm or physical or sexual violence. I am mandated to report concerns to the treatment team and to follow Fulton State Hospital policies and procedures. If they describe thoughts of or intention of committing any of the above-mentioned acts when meeting with me, I must report it.

Research contact information

You and your ward have the right to review the results of the research. Please contact me at XXX if you would like a copy of the results or if you have other questions.

This research study has been reviewed and Certified by the Institutional Review Board (IRB), Antioch University, Seattle. For research-related problems or questions regarding participants' rights, you can contact Antioch University's IRB Chair, Melissa Kennedy, PhD, at XXX.

Consent

I have read and understand the purpose of this research. I understand my ward's rights. I have been able to discuss this information and any questions with Alexa. My signature below indicates I consent for my ward to participate in this study according to the terms outlined above.

Even with my consent, my client will be able to complete this process with Alexa and sign their own consent form.

Print Name of Participant: ____

Print Name of Guardian: ______________________________

Signature of Guardian: _______________________________ Date: __________

In addition, I consent to my ward being audio-taped (voice only) if they are selected to participate in an interview.

Signature of Guardian: _______________________________ Date: __________

Was this consent acquired verbally? Yes ☐ No ☐

If verbally acquired, Name of Witness: ________________

Signature of Witness: ___________________________ Date: __________

Guardian Phone Number: ____

(You will be contacted by phone if any confidential information has been breached.)

Is it OK to leave a voicemail message on this phone? Yes ☐ No ☐

To be filled out by Alexa --

I confirm that the guardian of this potential participant was given an opportunity to ask questions about the study. I confirm I have answered any questions to the best of my ability. I confirm they have not been coerced into giving consent. I confirm consent has been given freely and voluntarily. A copy of this Informed Consent Form has been provided to the guardian of this potential participant.

Print Name of Researcher: ____

Signature of Researcher: _____________________________________ Date: ____________

APPENDIX D

CONSENT TO PARTICIPATE IN RESEARCH - PARTICIPANT CONSENT

Purpose, duration, procedures

You are invited to participate in a research study. The purpose is to study quality of life of people who reside and receive treatment on The Social Learning Program (SLP) of Fulton State Hospital (FSH). I also seek to understand their lived experiences and how they have made sense of the quality of their lives.

If you agree, I will collect basic details about you from your hospital records. This will include age, gender identity, race/ethnicity, and level of education. It will also include mental and physical health diagnoses, admissions to FSH, length of current stay, date of admission to the SLP, guardianship status, and civil/forensic status.

You will be asked to complete the WHOQOL-BREF. This is a survey with 26 questions. The WHOQOL-BREF has four domains related to quality of life. It also includes one area covering overall quality of life and general health. These questions will require about 20 minutes, depending on your reading ability. I can read the questions aloud if needed.

A few people will be asked to do an interview with me. This will include questions about receiving treatment on the SLP. There will be questions about your quality of life. I will ask about how you have made sense of the quality of your life. The interview could take between thirty minutes and one hour. Interviews will be audio recorded.

You will receive $5 for just the survey or $15 for completing the survey and the interview.

Participant rights

This process is voluntary. You have the right to decline or withdraw from the research at any time without penalty.

Participation consequences and benefits

These discussions can be distressing. If at any time you wish to stop, please let me know. I will discuss using your treatment team for support if you are having a hard time. I will also include handouts about the stress recovery model.

Doing research on the SLP can help us see how this program affects quality of life. Hearing about lived experiences can help us understand how things are going for you and for other people who are on the SLP. These aspects can help us better serve you and other people who have similar needs. Another benefit would be the small monetary incentive.

Limits of confidentiality

All details provided will be treated confidentially. I will ask you to avoid using your name or the names of others in the recorded interview. Surveys will be de-identified and stored in a locked file cabinet. All recorded data from the interview will be encrypted and kept on my password protected computer. These will be stored for later analysis. Audio recordings will be deleted no more than one year following the interview. There are risks with digitally stored data. All participants will be informed in the unlikely event of a breach.

Research results will be anonymously reported. Some quotes from the interviews may be used in the final report. However, I will include the least amount of detail possible. This informed consent will be the only identifying information and will not be linked to anything else in the study. The informed consent will be stored in a locked file cabinet.

Clients on the SLP have a treatment team who provides care and assists with their treatment. There are also polices in place that provide guidance if a client has thoughts of or intention to commit self-harm or physical or sexual violence. I am mandated to report concerns to the treatment team and to follow Fulton State Hospital policies and procedures. If you were to describe thoughts of or intention of committing any of the above-mentioned acts when meeting with me, I must report it.

Research contact information

You have the right to review the results of the research. Please contact me at XXX or XXX if you would like a copy of the results or if you have other questions.

This research study has been reviewed and Certified by the Institutional Review Board (IRB), Antioch University, Seattle. For research-related problems or questions regarding participants' rights, you can contact Antioch University's IRB Chair, Melissa Kennedy, PhD, at XXX.

Consent

I have read and understand the purpose of this research. I understand my rights. I have been able to discuss this information and any questions with Alexa. My signature below indicates I consent to participate in this study according to the terms outlined above.

Print Name of Participant: ____

Signature of Participant: __________________________________ Date: __________

In addition, I consent to being audio-taped (voice only) if selected to participate in an interview.

Signature of Participant: __________________________________ Date: __________

Phone Number: ____
(You will be contacted by phone if any confidential information has been breached.)

Is it OK to leave a voicemail message on this phone? Yes ☐ No ☐

To be filled out by Alexa ---

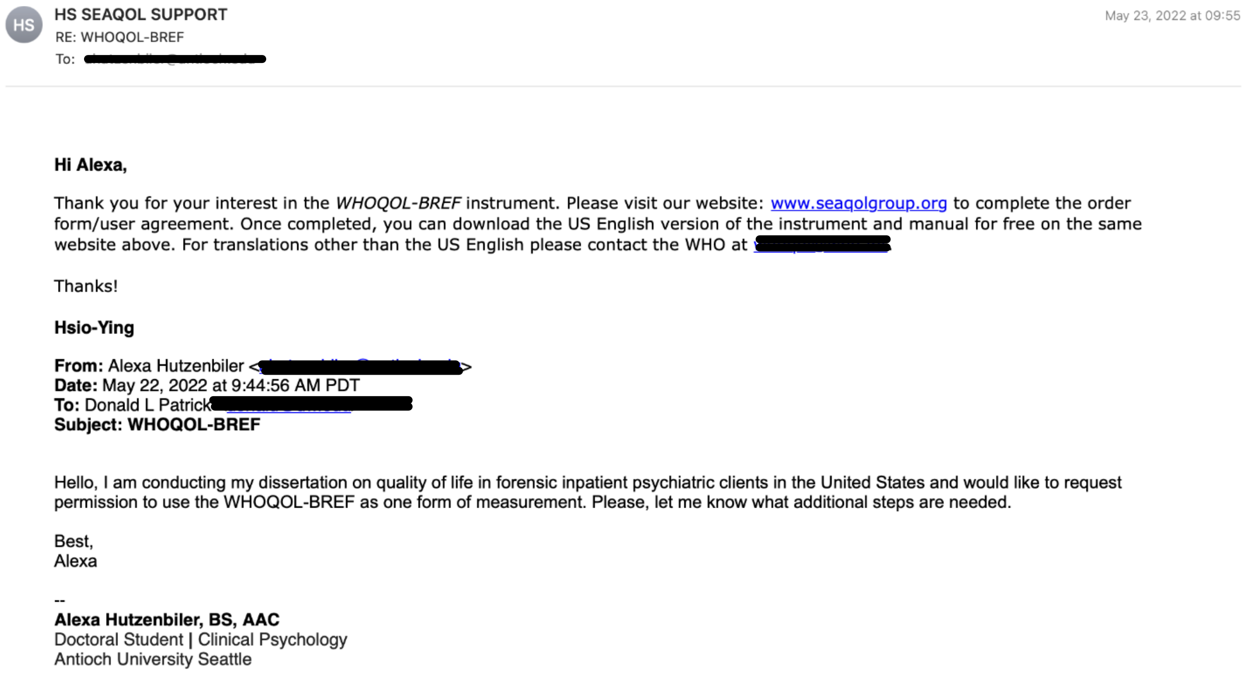
I confirm this participant was given an opportunity to ask questions about the study. I confirm I have answered any questions to the best of my ability. I confirm they have not been coerced into giving consent. I confirm consent has been given freely and voluntarily. A copy of this Informed Consent Form has been provided to this participant.

Print Name of Researcher: ____

Signature of Researcher: _____________________________________ Date: ____________

APPENDIX E

PERMISSIONS TO USE THE WHOQOL-BREF



HS **HS SEAQOL SUPPORT**
RE: WHOQOL-BREF
To: [redacted]

May 23, 2022 at 09:55

Hi Alexa,

Thank you for your interest in the *WHOQOL-BREF* instrument. Please visit our website: www.seaqolgroup.org to complete the order form/user agreement. Once completed, you can download the US English version of the instrument and manual for free on the same website above. For translations other than the US English please contact the WHO at [redacted]

Thanks!

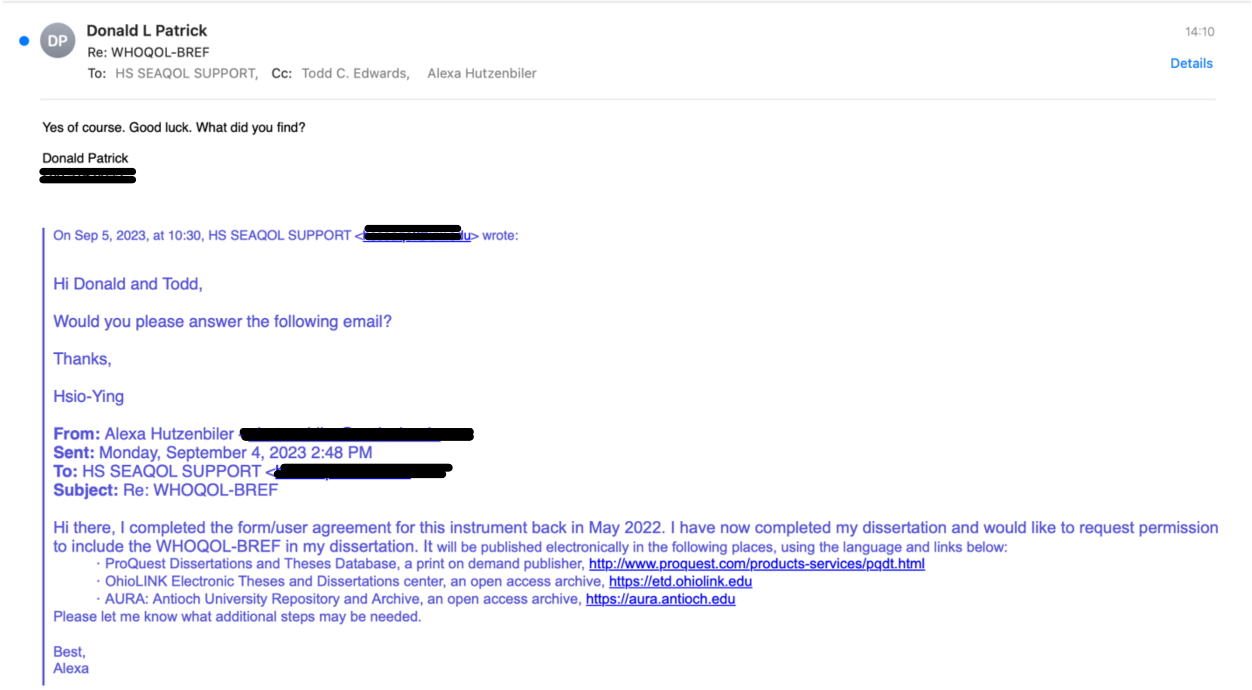
Hsio-Ying

From: Alexa Hutzenbiler <[redacted]>
Date: May 22, 2022 at 9:44:56 AM PDT
To: Donald L Patrick[redacted]
Subject: WHOQOL-BREF

Hello, I am conducting my dissertation on quality of life in forensic inpatient psychiatric clients in the United States and would like to request permission to use the WHOQOL-BREF as one form of measurement. Please, let me know what additional steps are needed.

Best,
Alexa

--
Alexa Hutzenbiler, BS, AAC
Doctoral Student | Clinical Psychology
Antioch University Seattle



DP **Donald L Patrick**
Re: WHOQOL-BREF
To: HS SEAQOL SUPPORT, Cc: Todd C. Edwards, Alexa Hutzenbiler

14:10
Details

Yes of course. Good luck. What did you find?

Donald Patrick
[redacted]

> On Sep 5, 2023, at 10:30, HS SEAQOL SUPPORT <[redacted]> wrote:
>
> Hi Donald and Todd,
>
> Would you please answer the following email?
>
> Thanks,
>
> Hsio-Ying
>
> **From:** Alexa Hutzenbiler [redacted]
> **Sent:** Monday, September 4, 2023 2:48 PM
> **To:** HS SEAQOL SUPPORT <[redacted]
> **Subject:** Re: WHOQOL-BREF
>
> Hi there, I completed the form/user agreement for this instrument back in May 2022. I have now completed my dissertation and would like to request permission to include the WHOQOL-BREF in my dissertation. It will be published electronically in the following places, using the language and links below:
> · ProQuest Dissertations and Theses Database, a print on demand publisher, http://www.proquest.com/products-services/pqdt.html
> · OhioLINK Electronic Theses and Dissertations center, an open access archive, https://etd.ohiolink.edu
> · AURA: Antioch University Repository and Archive, an open access archive, https://aura.antioch.edu
> Please let me know what additional steps may be needed.
>
> Best,
> Alexa

APPENDIX F

WHOQOL-BREF ITEMS

Overall
G1.1/B1 How would you rate your quality of life?
G2.3/B2 How satisfied are you with your health?

Domain 1: Physical
F1.2.5/B3 To what extent do you feel that physical pain prevents you from doing what you need to do? REVERSE
F13.1.4/B4 How much do you need any medical treatment to function in your daily life? REVERSE
F2.1.1/B10 Do you have enough energy for everyday life?
F11.1.1/B15 How well are you able to get around?
F4.1.1/B16 How satisfied are you with your sleep
F12.2.3/B17 How satisfied are you with your ability to perform your daily living activities?
F16.2.1/B18 How satisfied are you with your capacity for work?

Domain 2: Psychological
F6.1.2/B5 How much do you enjoy life?
F29.1.3/B6 To what extent do you feel your life to be meaningful?
F7.1.6/B7 How well are you able to concentrate?
F9.1.2/B11 Are you able to accept your bodily appearance?
F8.2.1/B19 How satisfied are you with yourself?
F10.1.2/B26 How often do you have negative feelings such as blue mood, despair, anxiety, depression? REVERSE

Domain 3: Social Relations
F17.1.3/B20 How satisfied are you with your personal relationships?
F3.2.1/B21 How satisfied are you with your sex life?
F18.2.5/B22 How satisfied are with the support you get from your friends?

Domain 4: Environmental
F20.1.2/B8 How safe do you feel in your daily life?
F27.1.2/B9 How healthy is your physical environment?
F23.1.1/B12 Have you enough money to meet your needs?
F25.1.1/B13 How available to you is the information that you need in your daily-to-day life?
F26.1.2/B14 To what extent do you have the opportunity for leisure activities?
F21.2.2/B23 How satisfied are you with the condition of your living place?
F24.2.1/B24 How satisfied are you with your access to health services?
F28.2.2/B25 How satisfied are you with your transport?

APPENDIX G

SCREENING QUESTIONS

- Are you fluent in English?
- Have you ever obtained Level II status on the SLP?

APPENDIX H

DEMOGRAPHIC INFORMATION TO BE COLLECTED FROM MEDICAL/ARCHIVAL RECORDS

- Age and Date of Birth
- Gender
- Race/Ethnicity
- Education
- Physical Health Diagnoses
- Mental Health Diagnoses
- Current SLP Level
- Highest Achieved SLP Level
- Length of current admission
- Length of treatment on the SLP
- Guardianship status
- Forensic/Civil status

APPENDIX I

INTERVIEW SCHEDULE

As noted in the methodology section, some of these questions may be modified based on participant understanding and ability to answer. The rewording of these questions will not impact the content of what is being asked.

The researcher will ask the following questions:

- Can you share about the process of coming in to the hospital and eventually this ward? How have you dealt with it? How has it impacted your quality of life?
- What has your experience been like since you have been here on this ward?
  - What has stood out to you?
- Tell me about the token economy?
  - What is that like for you?
- What level are you now? What is it like being this level?
- What is it like to be a Level IV versus being a Level III? (or any variation of X versus X)
  - How has the increase in level impacted your quality of life?
  - How do you plan to get to Level IV?
- What has your experience been like in your treatment classes?
  - Is there anything in particular that has been especially impactful or that you will take with you after discharge?
- How could this treatment be adjusted to better your quality of life?
- Tell me about your interactions with your treatment team?
  - Social work, psychology, psychiatry
- Tell me about your relationships with other people on the ward?
  - Staff, peers
- To what extent do you have the opportunity for leisure activities?
- How do you feel about the physical environment here?
- Can you perform your own activities of daily living? (taking care of your hygiene, cleaning up your own spaces)
  - Are you satisfied with your ability to do these activities?
- To what extent do you find your life to be meaningful? (How do you find meaning in your life?)
- Tell me about your current mood?
- One of the goals of this ward and this hospital is to help you be successful when you go back into the community. What do you think of this goal?
  - Does this resonate with you?
- Is there anything else that you would like to share with me about your experience?

APPENDIX J

WHOQOL-BREF ITEM SCORES BY PARTICIPANT

	Participant ID										
Domain / Item	1A	2B	3C	4D	5E	6F	7G	8H	9i	10J	11K
Overall											
G1.1/B1	3	2	4	1	5	5	4	4	2	4	5
G2.3/B2	2	1	4	4	5	5	4	4	5	4	4
Domain 1: Physical											
F1.2.5/B3 (r)	2	3	2	5	2	5	5	2	3	3	4
F13.1.4/B4 (r)	1	2	2	3	1	2	4	2	1	3	5
F2.1.1/B10	3	1	4	2	5	5	4	1	4	3	2
F11.1.1/B15	2	4	3	1	5	5	4	3	4	3	4
F4.1.1/B16	2	2	4	4	5	5	4	3	2	4	5
F12.2.3/B17	4	2	4	5	5	5	4	3	4	4	3
F16.2.1/B18	3	4	2	1	5	5	4	5	5	3	5
Domain 2: Psychological											
F6.1.2/B5	4	5	3	2	5	5	4	5	5	4	4
F29.1.3/B6	4	3	5	3	5	5	2	4	5	4	5
F7.1.6/B7	3	4	3	1	5	5	4	3	4	4	5
F9.1.2/B11	5	2	5	5	5	5	4	2	5	4	4
F8.2.1/B19	5	4	2	3	5	5	4	4	4	4	5
F10.1.2/B26 (r)	4	5	4	3	5	4	4	4	4	4	2
Domain 3: Social Relations											
F17.1.3/B20	4	4	2	3	5	5	4	4	2	4	3
F3.2.1/B21	1	4	2	2	5	5	4	4	4	3	5
F18.2.5/B22	2	4	2	2	5	5	4	4	5	4	3
Domain 4: Environmental											
F20.1.2/B8	2	1	2	1	4	5	4	3	2	4	3
F27.1.2/B9	2	2	2	4	5	5	4	3	5	4	4
F23.1.1/B12	5	4	4	5	5	5	2	2	4	3	5
F25.1.1/B13	2	2	3	2	5	5	2	2	5	5	2
F26.1.2/B14	2	3	4	2	4	5	4	5	2	3	4
F21.2.2/B23	2	4	3	2	5	5	4	3	4	5	2
F24.2.1/B24	4	4	4	3	5	5	4	4	4	4	3
F28.2.2/B25	2	4		5	5	5	4	2	5	4	5