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Enhancing Choice, Capabilities, and Community for Chronically Mentally Ill Persons:
The Social Context of a Faith-Based Day Program

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ABSTRACT

In the 21st century, the majority of chronically mentally ill persons live in the wider deinstitutionalized community and are receiving community-based care. In most cases, they lack positive social supports that would allow them to thrive in the community in which they reside. This study focuses on the social world of a faith-based day program, referred to as the Oaks, in the Atlanta metropolitan area that provides opportunities for participants to thrive via enhanced capabilities, maximizing choice, and engagement in the community at the center. Comprised of three original empirical research papers, this qualitative project explores the social community at the Oaks. The first paper is a thematic analysis study that examines the role of the Oaks as a mediating structure that leads to what we refer to as enhanced capabilities. The second paper is a grounded theory study that explores how participants develop meaningful dyadic relationships with each other. The third paper is a thematic analysis that investigates how enhanced capabilities lead to engagement in the religious collectivity. Data were collected beginning in 2012 and ending in 2015. In total, the first author completed over 80 hours of participant observation, conducted 34 semi-structured interviews with program participants and key staff, and reviewed facility records. Through the development of theory and the extension of multiple conceptual frameworks, including mediating structures, the capabilities approach, and the social convoy model, we found that participants reach toward their maximum potential as equal persons in an environment that provides consistent opportunities for social interaction.

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Persons: The Social Context of a Faith-Based Day Program

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CHAPTER 1 INTRODUCTION

Today, the majority of chronically mentally ill persons live in the community (Mechanic & Rochefort, 1990). Once housed in insane asylums, or total institutions (Goffman 1961), this group of marginal and disenfranchised individuals must now navigate the community mental health care system. Arguably, living in the community is an improved option over residing in total institutions (Powers 2017), but even community-based care is proving problematic.

In the state of Georgia, there is currently a critical eye on the conditions of the chronically mentally ill in the community. Georgia agreed to radically overhaul the state's mental health system as a condition detailed in the settlement of a lawsuit filed by the federal government in 2010 (Judd 2017). Now being discharged from psychiatric facilities due to hospital closures and a decrease in available beds, these individuals have been moved to extended-stay motels. Even worse options implemented by the state include directions to homeless shelters and "Greyhound therapy," or one-way bus tickets out of town. Community-based care is not necessarily safer or more effective than institutionalization. Since 2014, an alarming 350 individuals in community-based care in Georgia have died; over five dozens of those deaths were due to suicide (Judd 2017), and most deaths were avoidable.

This is not only a continuing issue, but a long-term problem. Considering these appalling circumstances, there is a great need for improving the conditions

of chronically mentally ill persons. One such solution is development of social supports such as the Oaks,¹ the organization of study in this project. The Oaks is a faith-based day program catering to chronically mentally ill persons in the Atlanta metropolitan area. The organization was developed in 1996 to address a social problem that continues today: the chronically mentally ill living on the streets. When the Oaks was founded, there was a mission to “sweep the streets” (personal communication from the vicar of the Oaks) and find a place to house the chronically mentally ill during the day (at night many were sleeping in shelters). The Oaks has been so successful in providing a positive environment where this population thrives that it has been in continuous operation for over 20 years. The permanence of the social support provided at the center underlies the positive social experience of the participants who attend.

The primary goal of this dissertation is to understand the social worlds of the chronically mentally ill within the context of a faith-based program. This is an ethnographic case study that focuses on several aspects of both participants’ experiences at the Oaks and the social institution that underlies those experiences. We explore the role of the Oaks in aiding participants to reach toward their maximum potential, the dyadic social relationships among participants, and their experiences in participating in religious practices within the context of the Oaks’ community.

This dissertation is organized as follows. First is the presentation of the history of deinstitutionalization that led to the current conditions for chronically

¹ All names are pseudonyms

mentally ill persons in the community. Following this introduction are three empirical papers consisting of original research on three topics relating to the social worlds of the chronically mentally ill attending a faith-based day program in the Atlanta metropolitan area. All three papers are first-authored by S. Megan Smith, with additional consultation, support, and revisions from co-authors Ellen Idler and Molly Perkins. The first empirical paper adopts a hybrid, i.e., a deductive and inductive, methodological approach. This paper highlights the social structure that underlies the social community at the Oaks. The conceptual framework builds on a mediating structures (Berger 1976) and capabilities approach (Nussbaum 2011). We developed a conceptual model outlining how one mediating structure, the Oaks, provides a structure that enhances the capabilities of participants at the Center. The second empirical paper is a grounded theory study focusing on the dyadic social relationships among participants at the Center. We constructed a theoretical model explaining the process whereby participants maximize choice within the context of the Oaks. This choice leads to the development of meaningful social relationships among participants. The third empirical paper is thematic analysis focusing on religious participation at the Oaks. The driving conceptual frameworks are the capabilities approach (Nussbaum 2011) and a Durkheimian perspective on the collective expression of religion (1961 [1912]). We maintain that participants engage in the collectivity at the Oaks through corporate religious worship and practice of religious rituals.

Subsequent to the three original empirical papers is a discussion chapter that highlights three overarching themes offered in the papers: enhanced

capabilities, maximizing choice, and engagement in the collectivity. Following the discussion are two sections suggesting practical implications and future directions, respectively. A brief conclusion summarizes the main points of the dissertation in its totality.

Deinstitutionalization

Deinstitutionalization is one of the largest social reforms in this country's history. It is estimated that over 450,000 mental patients were discharged from psychiatric hospitals between 1955 and 1974 (Mechanic & Rochefort 1990; Powers 2017). There are two medical reasons for this. First, new psychotropic medications were developed that could be distributed in medical clinics; they were not limited to distribution in institutions. Also, a group of drugs referred to as phenothiazines, namely Thorazine, were invented (Mechanic and Rochefort 1990; Rochefort 1984), which gave hope to medical professionals and families that life outside the institution was now possible; unpredictable or violent behavior could now be modified. While these medical advances resulted in the closing of many psychiatric institutions and movement of their patients into the community (Community Mental Health Centers Act, Title II P.L. 88-164), there were several social forces that collectively affected this reform to an even greater extent than medical technologies.

Initially, World War II (WWII) alerted the country to mental health needs and highlighted the need for prevention and treatment (Grob 1987; Mechanic 1969). An alarming number of men were rejected from serving in WWII, and over 40% of the total rejections were due to mental illness. Approximately

2,000,000 men were either denied entry or discharged from the service due to mental disability, which accounted for more men than were stationed in all of the Pacific (Brand 1965; Rochefort 1984). This indicated to military mental health workers that many psychiatric problems were due to either preexisting conditions or were a result of war experiences. The result of such findings were changes in therapeutic care for veterans, which ranged from hypnosis to group therapy (Rochefort 1984). Unfortunately, there was no additional outpatient care provided for individuals rejected from serving (Brand 1965). Even among veterans, there were challenges with providing treatment as there were only 3,000 psychiatrists in the country at that time. By 1964 there were over 17,000 psychiatrists (Mechanic 1969), which allowed access to treatment in the community for a wider range of the mentally ill.

During WWII, about 3,000 conscientious objectors, including many Quakers and Mennonites, were assigned to volunteer at 62 state mental hospitals (Grob 1987; Rochefort 1984). Charlie Lord, one such objector, photographed the deplorable conditions in closed psychiatric wards. These photographs were eventually published in *Life* magazine in 1946 in conjunction with an article written by Albert Maisel, titled “Bedlam USA,” and were greeted with public outcry (Taylor 2009). Another widely-read article in *Reader’s Digest*, entitled “The Shame of Our Mental Hospitals,” also garnered attention. As Ridenour (1961:107) explains, “These two articles, appearing in two of the magazines with the widest circulation in the United States, triggered a volcano of exposés and feature articles in other magazines and the daily press, which continued for

years.” In addition to exposés found in periodicals, there were several influential books and movies that highlighted the conditions of psychiatric hospitals, including Mary Jane Ward’s book *The Snake Pit* (1946) followed by the movie in 1948 by the same name, Mike Gorman’s *Oklahoma Attacks Its Snake Pits* (1948), and Albert Deutsch’s *The Shame of the States* (1948).

Deutsch (1948) features case studies of several state mental hospitals around the country, but perhaps his most scathing review is of Georgia’s state mental hospital in Milledgeville, which confirms Georgia’s checkered past of caring for the mentally ill. At the time, the mental hospital housed 9,000 patients; it was the largest of its kind in the world (Deutsch 1948). He argues that the State Mental Hospital of Georgia, or Milledgeville, as it was commonly referred to, was the worst of the 190 state mental hospitals in operation at the time. Although he does not explicitly state what “worst” means, his descriptive account of what he witnessed supports his claim. Deutsch argues that the institution was “backwards” and that the “most up-to-date building I saw under construction at Milledgeville, at a cost of \$450,000, was intended to house the criminally insane!” (p. 93) He indicated to his tour guide that he would be inclined to commit a crime if he were living in one of “Milledgeville’s old firetraps” just so he could reside in this new building. Apparently, the state was only willing to financially support a building for the criminally insane, but not for any other group of patients. Additionally, Jim Crow separated African-Americans from whites who were residing in different wards. The African-Americans were living in bug and vermin infested surroundings. In some instances, they were drinking

out of emptied food tin cans for a month at a time. Needless to say, conditions at Milledgeville, like other state institutions, were deplorable.

Following WWII was the inception of the National Mental Health Act of 1946, which was unfunded by the federal government despite its good intentions. As Brand summarizes, “The National Mental Health Act did not provide the Federal Government with authority to cope with the nation’s total treatment problem in mental illness” (Brand 1965:243). Nor did it equip the state governments to meet their patient problems. The goal was to provide research fellowships to undergraduates and graduate students, train mental health care professionals, and support the movement of mental health care to the states. The Act also proposed the development of the National Institute of Mental Health, (Brand 1965). Although not initially funded, the initiatives of this bill were realized shortly thereafter when funding came through.

The National Institute of Mental Health was funded in 1949 as a response to the mental health related events made apparent during WWII. It encouraged research on the effects of life in institutions. Just as the photographs from the conscientious objectors alerted the public about the challenges the mentally ill faced in psychiatric hospitals, so did this academic research. While academic research was not focused on the sensationalism associated with mainstream publications, it did shed light on life inside an institution, about which the public was previously unaware. The NIMH represented a growing involvement of the government in mental health. This is seen in the budgets of the NIMH in 1950, 1960, and 1967. From less than nine million dollars in 1950, it grew to 68 million

in 1960 and to 338 million dollars in 1967 (Mechanic 1969). Today, the NIMH budget is 1.4 billion dollars (NIMH 2015).

A classic piece of scholarship that portrayed life inside the institution was *Asylums* (1961), a collection of essays written by sociologist Erving Goffman. Goffman worked as an employee at St. Elizabeth's Hospital in Washington, D.C., a psychiatric hospital caring for about 7,000 individuals. During his fieldwork, Goffman portrayed the life of an "inmate" and wrote extensively on the characteristics of "total institutions," or physical places where all spheres of life take place. This extraordinary book portrayed the reality of life inside a psychiatric hospital.

This was a time that witnessed the rise of community studies including *Social Class and Mental Illness* (1958) by Hollingshead and Redlich, the "Midtown Manhattan Study" (1962) by Leo Srole and colleagues, and the Stirling County study (1963) by Leighton et al. In *Social Class and Mental Illness*, Hollingshead and Redlich reviewed the records of a number of hospitals, clinics, and private practitioners in New England and New York. The authors found that a disproportionate number of persons with emotional problems came from lower social classes. Research of this kind did not prove that poverty caused mental illness because it was possible that individuals fell from higher income levels because of mental disability. It did more clearly establish an empirical relationship between social class and psychiatric problems. By reaching beyond those persons already in treatment, the "Midtown Manhattan Study" went even further in demonstrating the presence of this link. Within a scientifically drawn

sample of the general population of Manhattan, Srole and his colleagues again found that lower socioeconomic groups exhibited higher rates of mental illness. Interestingly, Srole et al. (1962) reported that higher socioeconomic groups were more likely to receive treatment. The Stirling County study was similar to the Midtown Manhattan study in that the sample was drawn from the general population of a rural area in New England. Findings indicated that better mental health was associated with higher socioeconomic class. About a third of the sample population showed significant impairment from psychiatric disorder (Leighton et al. 1963).

The Hoover Commission (1947) noted that aid to the states had been reduced significantly while research support had been developing. Individual states were becoming acutely aware of their personnel and financial limitations at the same that a tentative optimistic spirit was emerging in the mental health field because of reports of improved release rates with intensive personal care and drug therapies (Mechanic 1969).

The Mental Health Study Act was enacted in 1955; its main goal was to create an objective, thorough, nationwide analysis and reevaluation of the human and economic problems of mental health. The resulting Joint Commission on Mental Illness and Health issued a report, *Action for Mental Health* (1961). This document was a 10-volume study that assessed the current condition and resources for the mentally ill in the United States. *Action for Mental Health* stated that there was a need to reform the psychiatric health care system. Many

individuals residing in psychiatric institutions were capable of living in the community with the proper support.

The Community Mental Health Centers Act (CMHCA) (1963) was a result of this study. The intention of the CMHCA was to provide instrumental, informational, and emotional support to the seriously mentally ill living in the community. Although there had been “back door” deinstitutionalization occurring since 1955 as community mental health centers encouraged releasing less severe cases, the CMHCA resulted in a flood of front door discharges (Rochefort 1984). Hundreds of thousands of mentally ill individuals who were residing in psychiatric hospitals were now living in the community. The mentally ill were financially supported in part by Medicaid, which was an encouraging reason for states to not only discharge thousands of psychiatric patients, but also close down multiple psychiatric hospitals. In California, these actions were supported by the fiscally conservative who preferred to move the financial burden of the mentally ill from state hospitals to federal aid programs. Interestingly, there was also support from liberals who believed in protecting the civil rights of the mentally ill. The way to protect the mentally ill’s civil liberties was to release them into the community. Although deinstitutionalization was encouraged from multiple arenas, political, popular culture, and the academy, it was not a well thought out reform, or at the very least one could argue that there was minimal follow through (Torrey 2012).

Deinstitutionalization was a well intended reform, but the outcomes from the start have negatively affected both the mentally ill and society generally.

These outcomes are important to understand because they lend themselves to the support and creation of more innovated community centers, such as faith-based organizations, as a modern day social response to the failings of the CMHCA. According to E. Fuller Torrey, a social psychiatrist and author of *The Insanity Offense* (2012), the four major outcomes of deinstitutionalization are homelessness, incarceration, victimization, and violence. The magnitude of the problem, he states, is that there are 5,000,000 individuals in the United States with severe psychiatric disorders (schizophrenia, bipolar disorder, and depression with psychosis). Over 500,000 mentally ill individuals likely do not take medication and are in need of some form of assisted treatment. A startling 1%, or 50,000, individuals are overtly violent (Torrey 2012:5-6).

Torrey states that the “rise of mass homelessness closely parallels the emptying of the nation’s public psychiatric hospitals” (2012:124). Shortly after deinstitutionalization, there was a rise of psychotic individuals on urban streets. Studies show that at least one third of homeless men and two thirds of homeless women have severe psychotic disorders. (Early, 2006; Gelberg & Linn, 1988). These statistics suggest that approximately 175,000 homeless men and women with severe mental illnesses are living on the streets at any given time. In Massachusetts, for example, 27% of patients discharged from psychiatric hospitals became homeless within six months. In Ohio, a study showed that approximately 36% of patients had no known address shortly after discharge, which is a 9% increase over the statistics from Massachusetts. In New York, almost 40% of patients had no known address six months after discharge

(Belcher, 1988; Drake et al., 1989; Torrey, 2012). Torrey argues that leaving psychotic patients untreated and homeless has implications not only for the mentally ill, but also for the general population. Additionally, many mentally ill individuals with a history of homelessness also have a history of violence resulting in felony convictions.

Another outcome of deinstitutionalization is the dramatic increase in the mass incarceration of the mentally ill in jails and prisons. This increase became apparent as early as the 1970s. Between 20% (NAMI 2014) and 22% (NAMI 2015) of seriously mentally ill people have been arrested at least once. Currently, it is estimated that between 21% of inmates in jails and prisons are mentally ill (NAMI 2017). This equals approximately 400,000 mentally ill inmates in the United States penal system. In the Georgia prison system, the number of inmates being treated for mental illness increased 73% between 1999 and 2006 (Simmons, 2006). These statistics indicate that jails and prisons have become the largest psychiatric institutions in the United States. As Torrey indicates, “There are now more mentally ill individuals in the Los Angeles County Jail, Chicago’s Cook County Jail, and New York Riker’s Island Jail than in any psychiatric hospital in the nation” (Torrey, 2012:129). Unfortunately, personnel are not trained to properly work with the mentally ill, who often become victims of abuse and violence in these institutions.

Victimization is yet another consequence of deinstitutionalization. Symptoms of severe mental illness, such as confusion and disorientation, leave many mentally ill individuals vulnerable. This impaired judgment can lead them

unknowingly into dangerous situations. Other symptoms of their mental illness, including mania and paranoia, make them targets of retaliation by others who may not know they are mentally ill. They are often marks for violent crimes such as assaults, rapes, and even homicides (Torrey, 2012). Mullen and colleagues (1999) found that the sicker people are, the more likely they are to be victims of crimes. One of the purposes of psychiatric hospitals was to provide protection for the mentally ill. When they were released into the community untreated, they were vulnerable to attacks from both criminals and other mentally ill individuals. In his book *The Insanity Offense*, Torrey (2012) provides example after example of individuals, particularly mentally ill women, who were victims of violent crimes. Many were raped, assaulted, and then killed. This was especially true of the homeless.

Violence is the fourth outcome of deinstitutionalization. According to Torrey (2012), “among the consequences of failing to treat individuals with severe mental illnesses living in the community, violent behavior and homicides are the most alarming” (p.140). Scholarship shows that rates of violence among the mentally ill are disproportionate when compared to the general population. In the seminal article by Swanson et al. (1990), evidence shows that those with bipolar disorder and schizophrenia, who are more likely to have symptoms of psychosis than other disorders, have prevalence rates of 11-12% for violence in the past year compared to 2% in those who were not diagnosed. The sample is drawn from the Epidemiology Catchment Area (ECA) studies. Link and Steuve (1995) found that there is a modest relationship between psychosis and violence.

More specifically, violence increased when the psychotic individual perceived a threat from someone else. In support of the findings from these studies, Torrey argues “5%-10% of individuals with severe psychotic disorders will commit acts of serious violence each year” (2012:143).

There is another outcome of deinstitutionalization—one where the chronically mentally ill are thriving in the community (Hoff, Briar, Knighton, & Van Ry, 1992). With the help of rehabilitation services, the mentally ill are finding housing and employment, as well as increasing their social skills through case managers in the community. This is accomplished through day programs—social clubs, clubhouses, and faith-based day programs (Hoff et al. 1992). Yannos and colleagues (2001) found that social clubs served as places that taught life and social skills. In that study, it was observed that each “member” (i.e., a consumer who attends the social club) was assigned a day to greet other members that came to the program. Members were also responsible for activities such as preparing lunch for other members and staff. In the program mentioned and others, members also learned employment skills and some were able to gain sheltered workshop work or competitive employment (Estroff, 1971; Yannos et al., 2001).

The Oaks has been in continuous operation for over 20 years, primarily because of its unique characteristics as a faith-based organization. While the Center is a successful community support, we have found no reports that mention the Oaks as a potential model for addressing the gaps in the Georgia mental health care system. This is unfortunate as the Oaks years in operation indicate that the

positive aspects of the Center have contributed to positive mental health outcomes of the participants who attend this faith-based day program.

REFERENCES

- Deutsch, Albert. (1948). *The shame of the states*. Oxford, England: Harcourt Press.
- Belcher, J.R. (1988). Rights versus needs of homeless mentally ill persons. *Social Work* 33: 398-402.
- Drake, R.E., Wallach, M.A., & Hoffman, J.S. (1989). Housing instability and homelessness among aftercare patients of an urban state hospital. *Hospital and Community Psychiatry* 40: 46-51.
- Earley, P. (2006). *Crazy: A father's search through America's mental health madness*. New York: G.P. Putnam's Sons.
- Estroff, S. (1981). *Making it crazy: An ethnography of psychiatric clients in an American community*. Berkeley, CA: University of California Press
- Gelberg, L., and Linn, L.S. (1988). Social and physical health of homeless adults previously treated for mental health problems. *Hospital and Community Psychiatry* 39:510-516.
- Goffman, E. (1961). "Asylums: Essays on the social situation of mental patients. New York: Doubleday Anchor.
- Hoff, M.D., Briar, K.H., Knighton, K., & Van Ry, A. (1992). To survive and to thrive: Integrating services for the homeless mentally ill. *J. Soc & Soc. Welfare*, 19: 235.
- Hollinghead, A.B., & Redlich, F.C. (1958). *Social class and mental illness: A community study*. Hoboken, NJ: John Wiley & Sons.

- Judd, Alan. (2017). Disabled Georgians: Deaths, delay plagues Georgia reform-state send patients to extended-hotels, homeless shelters. *The Atlanta Journal Constitution* May, 14, 2017.
- Link, B.G., & A. Steuve. (1995). Evidence bearing on mental illness as a possible cause of violent behavior. *Epidemiologic Reviews* 17: 172-181.
- Mechanic, D., & Rochefort, D. (1990). Deinstitutionalization: An appraisal of reform. *Annual Review of Sociology* 16, 301-327.
- Simmons, A. (2006). Prisons see more inmates requiring mental health care. *Gwinnett Daily Post*. July 30, 2006
- Swanson, J.W., Holzer, C.E., Ganju, V.K., & Jono, R.T. (1990). Violence and psychiatric disorder in the community: Evidence from the Epidemiologic Catchment Area Surveys. *Psychiatric Services* 41: 761-770.
- Torrey, E.F. (2012). *The insanity defense: How America's failure to treat the seriously mentally ill endangers its citizens*. New York: W.W. Norton & Company.
- Yanos, P. T., Rosenfield, S., & Horwitz, A. V. (2001). Negative and supportive social interactions and quality of life among persons diagnosed with severe mental illness. *Community Mental Health Journal*, 37, 405-419.

CHAPTER TWO

ENHANCING THE CAPABILITIES OF THE CHRONICALLY MENTALLY ILL THROUGH THE MEDIATING STRUCTURE OF A FAITH-BASED DAY PROGRAM

ABSTRACT

How to best care for the chronically mentally ill is a pressing contemporary social issue. Questions arise as to how to effectively serve this population given the constraints of the current health care system and the varied capabilities of these individuals. Small-scale community organizations, or mediating structures, that support this population may be well positioned to help develop the untapped capabilities of the chronically mentally ill. This qualitative study explores how one mediating structure that serves the chronically mentally ill facilitates the development of agency among its participants through fostering a sense of belonging and a stable social structure. Data were collected between 2012-2015 at a racially diverse faith-based day program in the Atlanta metropolitan area. Developing a conceptual model that combines the concept of mediating structures and the capabilities approach indicates that mediating structures allow the empowerment of this marginalized community by enhancing its members' distinctive capabilities.

KEYWORDS

Mediating structures, capabilities approach, mental illness, qualitative methods

INTRODUCTION

One in four individuals will be diagnosed with a mental illness during their lifetime. One in 20 Americans currently live with serious chronic mental illness, such as schizophrenia, bipolar disorder, or major depressive disorder (National Alliance on Mental Illness, 2017). Often policies focus on simply providing services to the chronically mentally ill, but do not address structures that allow these individuals to meaningfully participate in their communities.

Mediating structures “are those institutions which stand between the individual in his private life and the large institutions of the public life” (Berger & Neuhaus, 1977:2) and include religious organizations, voluntary associations,

neighborhoods and ethnic communities, and families. The concept of mediating structures was coined by Berger & Neuhaus (1977), who drew from the classic sociological works of de Tocqueville (1945 [1835]) and Durkheim (1951 [1897]). These mediating structures provide a sense of belonging to individuals who are subsequently empowered to reduce stigma, maintain employment, and improve living situations.

Building on a larger study that investigated the nature of social support networks and social relationships among a group of chronically mentally ill persons, the aim of this analysis is to investigate and outline how a day program providing support to a diverse group of participants in the metropolitan Atlanta area operates and provides support as a mediating structure. This descriptive qualitative study incorporates the capabilities approach, which extends the concept of mediating structures. The goal is to develop an explanatory model employing inductive and deductive approaches to inform theory, policy, and practice.

THEORETICAL FRAMEWORK

Mediating structures provide unique contexts that may influence, or “mediate,” how individuals engage with society and social problems, and often serve as practical bridges between individuals and society (Mendel, 2003, Todd & Allen, 2011). From the point of view of the individual, these institutions offer the opportunity for close, face-to-face contact with people with whom one shares a sense of belonging. Mediating structures contribute to the well-being of the individual and the moral integrity of the larger society (Kerrine & Neuhaus,

1979). They constitute groups in which individuals are members, have roles to play, and have rights and obligations to others.

Mediating structures are community organizations that are situated between the large institutions of modern life and the individual. Upwardly, they face the large, impersonal "megastructures" of societies that include the economic conglomerates of capitalist enterprise and growing private and public bureaucracies that administer wide sectors of society, such as education, organized labor, and health care (Berger & Neuhaus, 1977, Levin & Idler, 1981). Such large, complex entities lose their touch with individuals, are alienating, and devoid of personal meaning. Megastructures cannot provide the social integration and regulation that individuals need in daily life. Conversely, in the private sphere of families, friends, and neighbors, individuals find meaning, fulfillment, and personal identity (Berger & Neuhaus, 1977). Individuals associate their personal identities with their role in relationship with others (e.g., friend or spouse) instead of identifying with their roles within megastructures (e.g., a patient in the healthcare system). According to Levin and Idler (1981), the sense of identity historically derived from one's occupation and the place this gave the individual in the community is now more often derived from the small group of people comprising the individual's private life. The precariousness of this aspect of the social order can lead to anomie, or a "lack of one's self and one's place in society" (Levin & Idler, 1981:6). There is a chasm and a tension between public and private life, and mediating structures fill this gap.

Mediating structures are groups such as neighborhood and community

organizations that people affiliate with voluntarily. Individuals have familiar face-to-face relationships with others in these groups, and at the same time such groups are recognized in their communities as representing the interests and views of their members. In this way, such groups provide a sense of belonging at the community level, prevent feelings of isolation, and provide a set of social norms that guide human behavior.

Sociologist Emile Durkheim first wrote about these types of structures in his study of social suicide rates, which indicated that variations in suicides were highest among those who were isolated and participated least in social life; these individuals lacked social integration. Social factors, he argued, were more telling of suicide rates than any others, such as physiology, insanity, race, heredity, and climate (Durkheim, 1951[1897]). Individuals living in societies of anomie, a space of meaninglessness and normlessness, were most likely to commit suicide (Durkheim, 1951 [1897]). In the context of understanding the chronically mentally ill, mediating structures, most often in the form of religious organizations, serve as fundamental supports to this vulnerable population.

Religious Organizations

Sider and Unruh (1999) identify three types of faith-based organizations (FBOs): religiously affiliated providers who employ secular approaches only, religiously affiliated providers who rely on religious approaches to the exclusion of traditionally secular approaches, and integrated faith-based providers who combine religious and secular approaches. One form of FBOs are urban social ministries providing community services to marginalized populations (Castelli &

McCarthy, 1997). These types of social ministries provide services ranging from transportation, to recreation/social activities, to social support (Boykin & Thomson, 2007). The mediating structure that is the subject of this study is an urban, social ministry that serves as a community support through an integrated approach (i.e., religious and secular) to achieve health and wellness.

Leavey and colleagues (2012) highlight the importance of the community building and cohesion in which clergy and FBOs tend to quietly engage; the long-standing health and welfare patchwork provided as part of ministry; and meeting the gaps that the government leaves behind or is unable to fill. Some FBOs view mental illness as a moral or spiritual problem and therefore want to take responsibility for providing care for this vulnerable population (Dossett, et al., 2005). Several studies (Boykin & Thompson 2007; Dossett et al. 2005; Leavey et al. 2012) indicate that clergy currently play an important role in the provision of mental health services and that their involvement may not be limited to minor mental health disorders.

Limited scholarship focuses on the role of FBOs in supporting the mentally ill (Boykin & Thompson, 2007, Dossett, et al., 2005, Leavey, et al., 2012). In the only empirical study identified on FBOs catering to the mentally ill, Dossett and colleagues (2005) surveyed attitudes toward mental health services and identified barriers to providing these services within the agencies comprising the QueensCare Health and Faith Partnership in Los Angeles, CA. The common denominator of this network of FBOs is that they provide general health care services to low-income, ethnically diverse residents of Los Angeles. While some

of the organizations provided only physical health care services, most were interested in providing mental health services as well. However, there was a great degree of variability in opinions within the organization about the etiology of mental illness (i.e., a belief in a medical model of mental illness versus mental illness as a spiritual/moral problem). These differing belief systems resulted in varying strategies used to treat mental health needs (i.e., interventions versus counseling). Despite these divergent ideologies, the general consensus of the participants in the study is that there is a definite need for mental health care services for the underserved populations in the Los Angeles area (Dossett et al. 2005). While Dossett et al.'s study highlighted the importance of FBOs for providing health services, it did not take the perspective of the clients of the organization, or touch on the key question of the current study: how can chronically mentally ill individuals be empowered to maximize their potential capabilities?

Due to the limited scholarship in the area of mediating structures providing mental health care for the chronically mentally ill, more research is needed. This qualitative study attempts to understand how mediating structures provide a sense of belonging in these unique organizations and how this sense of belonging empowers the chronically mentally ill (Berger and Neuhaus 1977; Levin and Idler 1981; Walker 1992) and leads to enhanced capabilities (Nussbaum 2011). It is critical to recognize that the focus on public policy that dominates scholarship on mediating structures has not been applied to understanding the limited forms of empowerment achievable among the socially-disadvantaged chronically mentally

ill. However, this research will show that the concept of a mediating structure is useful in suggesting the forms of empowerment that are in line with chronically mentally ill individuals' capabilities.

The Capabilities Approach

The capabilities approach (Nussbaum 2011) is complementary to the concept of mediating structures in that it takes into account the differing, and sometimes quite limited, capabilities of individuals who nevertheless are capable of participating in a social organization. This hybrid approach explains why empowerment looks different among the chronically mentally ill.

Nussbaum defines the capabilities approach as, “an approach to comparative quality-of-life assessment” (Nussbaum 2011:18). I argue that this approach is relevant to a vulnerable population of chronically mentally ill adults who are socially and economically marginalized in most areas of their lives, except during their time at the Oaks. Their situation is similar to that of the oppressed groups in less developed nations on which Nussbaum focuses her work. She posits that measuring the health and well-being of the citizens of a particular country by the gross domestic product (GDP) is simply inappropriate; there must be a measure of quality-of-life to determine health and well-being.

The central question of the capabilities approach is, “what is each person able to do and to be?” This concept focuses on “choice or freedom” that societies should provide in the form of opportunities. Nussbaum argues that societies should offer opportunities that individuals may or may not choose to engage with: “the choice is theirs” (Nussbaum 2011:25). There are ten central capabilities,

which are required for individuals to reach their maximum potential for ultimate health and well-being, including, 1) *life*; 2) *bodily health*; 3) *bodily integrity*; 4) *senses, imagination, and thought*; 5) *emotions*; 6) *practical reason*; 7) *affiliation*; 8) *other species*; 9) *play*; and 10) *control over one's environment*. The capabilities listed here are often absent in the lives of chronically mentally ill adults for whom others are making decisions regarding medical treatment (for both physical and mental ailments), finances, living arrangements, and what to do in their leisure time. For most participants at the Center, there are no choices except when they are engaging in Center life.

LOCATION OF RESEARCH

St. Francis

The Oaks, an FBO providing health and wellness programs for a group of chronically mentally ill persons, is housed within St. Francis*, a church in the Episcopal diocese of Atlanta. The Center serves as a mediating structure in which participants feel a sense of belonging and identity, allowing them to feel empowered by reducing stigmatization and gaining social skills that allow them enhanced capabilities.

The Origins of St. Francis

St. Francis was founded in 1892. Forced relocation from the 1960s and 1970s due to interstate highway construction brought the parish into a neighborhood, Glendale Park, that became a location for the practice of “red-lining,” whereby African Americans were refused credit on a discriminatory basis because they were deemed a poor financial risk, and hence concentrated by

limited housing choice to remain in certain neighborhoods, including this one (i.e., African-Americans were red-lined into Glendale Park). Shortly following, "personal care homes" were established in the neighborhood to house the community dwelling mentally ill who had recently been deinstitutionalized. At the same time, "white flight" began, which negatively affected the membership of the church. Until the 1970s, the congregation of the church was mainly white middle-class and working-class individuals. By the mid 1970s, church membership had fallen to about 35 members with a one-quarter-time clergy (personal communication from the former vicar).

In 1982, the Bishop of Atlanta informed the parish that the diocese could no longer afford even Sunday supply clergy and that he would be forced to close down the church within the month. One of the part-time vicars requested a six month reprieve to see if the dying church could be revived. In the words of the canon missionary, who later became the vicar of the parish, the few families left prayed "that God would send them the people that no one else wanted" (personal communication from the former vicar).

Within a matter of weeks these prayers were answered as individuals with chronic mental illness from the nearby personal care homes accepted invitations by the vicar to attend Wednesday and Sunday services (personal communication with the former vicar). The church provided a safe space for new attendees to talk about their lived experiences, share coffee, and eat lunch. Thirty-five years later, the average Sunday morning attendance is approximately 75 people. It is a typical parish in that its members gather on Wednesday evenings for healing services and

a community supper and on Sunday mornings for Holy Eucharist. St. Francis is unlike most parishes, however, as the majority of parishioners live with chronic mental illness (personal communication with the former vicar).

The History of the Oaks

In late 1995, a state employee who was serving in the Office of Consumer Relations in Georgia's Division of Mental Health and was also a member of the Episcopal diocese learned from the food manager at an Atlanta psychiatric hospital that the institution was stocking up on extra food for when the 1996 Summer Olympics came to town (personal communication). The state's plan, according to the hospital's food manager, was to sweep the streets of all the homeless and mentally ill and house them in the two metro state psychiatric institutions during the Olympics so they would not create problems or be an eyesore while Atlanta was in the world spotlight (personal communication).

As someone in recovery from mental illness himself, the state employee was deeply troubled by this dehumanizing plan that perpetuated stigma and hopelessness (personal communication from the former vicar). He proposed an alternative to this plan to his supervisor. He knew of a program in Hamilton, Ontario called The Friendship Center (Meserau 1997). The Friendship Center was the vision of a married couple, one of whom was a psychiatrist working in the public mental health system, whose son was in recovery from schizophrenia. This Center provided support and a social place for the chronically mentally ill to spend time away from their group homes. The type of day program offered at the Ontario center became the template for the Georgia state health worker's

proposed center in Atlanta. In particular, the state worker adopted the open membership policy, art therapy program, and informal structure of the Ontario center, which were some of its most distinctive aspects. These programs provided a flexible space for adults with chronic mental illnesses to engage in activities and social interaction to the extent they wanted. In *Off the Streets*, a retrospective manual for developing programs like the Friendship Center, the founder reported “great enthusiasm!” about the development of such a program (Meserau, 1997:7). There was a definite need for more opportunities for higher functioning community-dwelling former psychiatric inpatients, and mental health professionals, such as psychiatric case managers, were delighted about another option for their unemployed clients who had little to do and few places to go.

The state worker in Atlanta saw the Friendship Center’s success as a powerful model for addressing the crisis surrounding the chronically mentally ill during the Olympics. After hearing about it, mental health professionals in Atlanta pleaded with several area churches to host similar programs every day during the Olympics. The programs were to be staffed by volunteers from their respective churches. These churches served as a welcoming place for socialization and shelter from the heat, stress, and trauma of the masses flooding the city during the 1996 Summer Games (personal communication from the former vicar). Five other churches joined the program. Over 500 mental health clients? participated in Friendship Center programs during the Olympics. Unfortunately, all of the centers closed following the Olympics (personal communication from the former vicar).

A short time after the Olympics, the priest at one of the churches that had sponsored a Friendship Center noticed that a cutback in state day programs for individuals with mental illness was resulting in some of his parish members becoming isolated in their group homes. The church supported reopening the Friendship Center at this one location. This center, which I refer to as the Oaks, now serves approximately 60-70 individuals on Tuesdays and Thursdays between 9 am and 2 pm. The Oaks provides transportation to the program, a hot breakfast and lunch, and programming between meals. Individuals are invited to work on art, reading, yoga, and other activities that support recovery.

The Structure of the Oaks

In an attempt to establish itself as its own entity for funding purposes, the structure of the Oaks has changed significantly since its inception. The newly formed Board of Directors and the vicar believe that the designation of the organization as a 501(c)3 will result in additional funding and increased support for the Oaks. The vicar manages the daily operations and oversees all staff, including program directors, the janitor, and the gardening staff, for a total of 18 paid personnel. Additionally, she oversees all volunteers, who range from participants to community members.

METHODS

Study Setting and Population

The Oaks serves a racially diverse group, primarily African-Americans and whites, living with chronic mental illness in the community. Anyone over the age of 18 is eligible to participate in the program. The program has no formal

membership process. Primary ways participants learn about the program are through social services agencies, group home providers and residents, and word of mouth.

The majority of participants have been diagnosed with schizophrenia, many with paranoid schizophrenia. Other common diagnoses include bipolar disorder and depression. Characteristics of the study population stay somewhat in flux due to patchy attendance by some, and others' entrance into and exit out of the program. Administrative data collected by The Oaks show that about 60% of the study population is African-American and 40% are white. Additional racial and ethnic groups attend, but they generally comprise less than 5% of the population. Men make up about 60% of the study population. Approximately 40% of participants are over age 50. More than 30% of the program participants have been homeless at one point in their lives and most participants in the program live at or near the federal poverty level, which is \$11,170 for a single resident household (Department of Health and Human Services, 2016).

Data Collection

Data collection began in 2012 and ended in 2015. The data we present here are based on 41 months of fieldwork that includes: participant observation, informal and in-depth interviews with seven program staff and twenty-seven participants, and a review of facility records. A range of participants was selected for formal interviews, representing a wide array of socio-demographic characteristics and varying levels of social involvement in structured and unstructured programming. Visits ranged in length from 1.5 to 5 hours (but were

typically 2.5 to 3 hours). In all, a total of 38 field visits were made for a total of 81 hours observing during the study period. Informal interviews were unstructured and carried out in the course of conducting observations. In-depth interviews ranged from 30 to 70 minutes, with an average time of 45 minutes, and were digitally recorded and transcribed verbatim. Interview guides had a semi-structured format consisting of an outline of issues relevant to the study aims of the larger study. This format allowed the first author to adapt the sequencing and wording of the questions to fit each unique interview situation and incorporate follow-up probes to obtain additional information or details as needed. Staff interview guides address services and policies; and the quality of staff-participant and participant-participant social relationships. They also include probes about mental health training and employment experiences. Participant interview guides include questions regarding mental health status and history, such as age of diagnosis and prior hospitalizations, and about their experiences and perceptions of the Oaks. Information collected from program records included an overall profile of The Oaks in a report by the center, which included census information describing the surrounding community and demographics of program participants, including information on previous homelessness. The Oaks also provided researchers with a copy of their mission statement, program vision, meeting agendas, and strategic plan, which included photographs (head shots) of participants, volunteers, and staff.

Data Analysis

We employed a thematic analysis approach, which is a common method used to identify and analyze recurrent themes and patterns in qualitative data (Patton 2002; Lofland et al. 2006). Using a deductive and inductive approach (Boyatzis, 1998; Fereday & Muir-Cochrane, 2006), coding involved both “top down” (theory-driven) as well as “bottom up” data-driven methods (Braun & Clarke, 2006). In the first stage of analysis, the first author created a codebook of a priori codes based on the study aims as well as concepts associated with the mediating structures and capabilities approaches. As analysis progressed, emergent themes were added to the codebook. All coding was performed by the first author; codes and emerging themes were refined and confirmed through regular meetings with co-authors. The final stage of analysis involved linking themes together to create an explanatory framework (see Figure 2.1) that describes how the Oaks operates as a mediating structure and works to enhance the capabilities of its participants. This model includes four interconnected main themes or features central to the Oaks role as a mediating structure: *addressing marginalization*; *promoting a sense of belonging*; *empowering participants*; and *enhancing capabilities*. We describe these themes and their subthemes below in more detail. The NVIVO11 software was used to manage and facilitate data analysis.

RESULTS

Addressing Marginalization

As illustrated in Figure 2.1, participants experience social and economic marginalization due to their diagnosis of chronic mental illness. Data collected

from the Oaks show that many participants have lived in poverty; more than 30% have been homeless at some point in their lives. Most participants receive Supplemental Security Income (SSI), which is not supplemented by Social Security or other types of income, and thus have monthly incomes of only \$710 (Social Security Administration, 2017). The majority of these individuals currently live in licensed and unlicensed (i.e., illegally-operated) small low-income personal care homes. In many cases, program participants use most of their monthly income to pay for board and care in these facilities (Georgia Department of Community Health, 2013). By law, residents must receive a small personal needs allowance of \$5 per week from their Social Security Payee, and many program participants have only this small stipend to pay for toiletries and other personal needs. In addition to other services, many receive clothing, toiletries, and help with showers and personal hygiene through the Oaks.

Carl, a 30 year-old African American male with schizophrenia, said about the effects of the onset of his illness had on his social and economic position:

It seemed like when the mental illness hit me, everything started going downhill for me for a while.

Mentally ill persons are often excluded from certain social groups due to their symptoms, stigma from the community, and as a byproduct of their co-morbid physical health issues. While participants rarely referred to the marginalization they experience, most participants were excluded from certain social groups, such as family. Most only saw family members “rarely,” “sometimes,” “once in a blue moon,” or they had not seen them in several years. Economically, according to Charlie, the former vicar, “they are...segregated by and large from the

mainstream economy.” This is because they lack education, are pushed into the lowest socioeconomic strata, and have few material resources. The staff is hyper-aware of these social conditions and they attempt to limit the overwhelming sense of marginalization they perceive is experienced by participants. Chelsea, the vicar, said about the way the Oaks addresses this marginalization:

I think, there has always been a sense of providing community and meaningful activities, to people with mental illness, particularly those in poverty, although, we don't have any participation criteria. That is what we tend to get [participants], because that is the population most underserved.

Promoting a Sense of Belonging

Attendance at the Oaks addresses marginality by promoting a sense of belonging and feeling a part of a “larger thing.” Participants feel like they belong to the Oaks, which leads to empowerment, resulting in enhanced capabilities. A former staff member, James, a middle-aged white male with a bipolar diagnosis, said about his positive experience working and participating in center life:

Everyday I go home and [have] dinner with my wife and I just tell her about some part of my day that I really loved. And that means a lot to me and that makes me proud, that larger thing.

According to the former vicar, the Oaks' goal is to create a community of belonging. This is an intentional act on part of the staff, who are sometimes at odds with members of community-based prevention teams situated in healthcare facilities, particularly healthcare professionals based in the county hospital and department of public health. Charlie, the former vicar said:

Our model is long-term community, and if you can fit that by bringing people...supporting them as a long-term member of this community, but if you are just bringing them in so you can bill Medicaid, and don't care if it is here today or gone tomorrow, you

are just disrupting what we are doing.

The “model of community” is successful as most feel a sense of belonging to the center. Daniel, a 35 year old African-American male with schizophrenia, said he recognizes the positive qualities of the center:

Coming here eating and just smoking cigarettes and just talking to the fellas and the young ladies...I know another center probably couldn't be better than this.

Some said that they would not “know what they would do” if the center closed. A few said that they would find another center to attend. One participant, Rex, a white man with bipolar disorder said, “Oh, I'd be distraught. I'd be really- I'd be unhappy.” One unintended outcome during several interviews was asking how participants “would feel if the center closed,” which caused distress among some respondents since this hypothetical question led them to falsely believe that the center might close. The first author stopped asking the question in future interviews because participants' reactions were so telling regarding their strong connection to and investment in the program.

Another way that participants feel a sense of belonging is through disclosure by staff about their own mental health diagnoses. This disclosure provides an automatic connection to staff, which eliminates a feeling of “us and them,” and the possible devaluation and discrimination that can occur in treatment settings. This mental health status disclosure by staff has the potential for role modeling, openness, and breaking down stigma. In an interview with James, the topic was discussed:

One of our administrators has a diagnosis of mental illness, our music therapist has a diagnosis of mental illness, one of our

deacons does as well, the priest's family has had some very direct impact with mental illness. There is not a sense of us and them.

Empowering Participants

A former staff member stated in an interview that the mission of the Oaks is to “to provide a community of support and empowerment for adults marginalized by poverty and mental illness.” This mission is achieved through programming efforts at the center and staff members “loitering with intent,” a term coined by the former vicar. The concept of loitering with intent means that staff members sit down and initiate conversations with participants about topics ranging from the weather to life in personal care homes.

The first author observed that participants feel empowered to make decisions and join in on activities on their own. This observation was confirmed by most participants' similar responses that they initiated involvement. For example, Roger said that he “joined [activities] on his own.” He further stated: “I decided [to attend an activity]. She didn't push no button. I decided to do it on my own.” Participants feel empowered by their ability to initiate involvement in programmatic activities, which leads to other, unintended mental health benefits, such as increased well-being as evidenced by the confidence in which they discussed this topic. The following excerpt from an interview illustrates the positive effect that program participation has had on one participant with paranoid schizophrenia.

Interviewer: Do you believe your life has changed as a result of participating in center activities?

Everett: Sure, yeah.

Interviewer: In what ways?

Everett: I feel like I'm more positive, more calmer and more

relaxed.

This process of empowerment manifests itself in variety of other ways, one of which includes what some program participants describe as “self-directed recovery.” As Victor, a 64 year old man recently in recovery from a manic episode in which he was incarcerated for several months, describes how the Oaks and its association with the nationally renown National Alliance for Mental Illness (NAMI) through which the Center hosts a weekly connection group, have assisted in his self-directed recovery:

I don't say it has made drastic changes in my life. It has helped to get me back to a recovery mode and...it kept me to focus on issues with my mental health. I have to place attention to and try to grow and learn and cope and apply the coping skills that I've been given from the Oaks and NAMI and the other support group to my daily life to be comfortable.

Some participants experience empowerment when they believe they can educate others about mental illness generally, and after trust is established, they can talk about their lived experiences. This sharing of stories helps participants build rapport with others and helps remove some of the self-imposed stigma.

Empowered with a strong voice and an expertise in a subject area (i.e., lived experiences), participants muster the courage to talk openly about their personal situations. Jack said:

And see, that's the goal that other people need to look at, though. Schizophrenia and stuff like that... see how it is for them, though. [Many people] don't understand mental illness. You've got to tell them.

He also believed that sharing his story with others contributed to “making good friends. I started having good friends. It's better to have some friends [than none

at all].”

One way that participants gain empowerment is through the NAMI connection group run by Susie, the health and wellness staff member, and Mary Arial, a volunteer at the Oaks. An excerpt from field notes describes an interaction J.C., a 33-year-old African-American male with bipolar disorder who works as a gardener, had with Randy, an African-American male who is a staple in the smoking section during program days and rarely participates in any structured programming. J.C. talked to Randy about the benefits of participating in the NAMI connection group.

A group of men, mainly those from the Toney House, are sitting on the picnic tables smoking. J.C. is talking to Randy about his recent trip to St. Simons through the NAMI [connection group]. J.C. says, “Man, you really ought to think about going. It’s really helpful and fun. They’ve got good food. Plus, the groups are really good. They teach you skills about how to handle your emotions.”

Field notes recorded later that day detail an impromptu meeting Laney organized with the gardeners. She encouraged the gardeners who attended the NAMI annual statewide conference to talk about their empowering experiences at the conference. NAMI’s central goal is to advocate for and educate individuals about mental illness. They have a strong presence at the state and national level in terms of their lobbying efforts to protect the rights of mentally ill persons. During the meeting, both Laney and the other participants who attended the conference encouraged the other gardeners who did not attend the NAMI event to participate in the NAMI connection group in the future so that they would be eligible to attend the annual conference the following August. The following excerpt from

field notes describes that exchange:

During [their] break [from gardening], Laney has some of the gardeners...talk about their trip to St. Simons- what they liked and what they learned. J.C. goes first. He talks about the value of the sessions and how he learned some coping skills to deal with the symptoms of his mental illness. Clay talks about how much he liked the keynote speaker and how he could relate to him. He, too, had feelings of anger about his mental illness and found it helpful that he wasn't alone in his thoughts and feelings about mental illness. Laney told a story about how she thought she was going to one session, but ended up in a session that talked about values. "You know you always think about values as being something more serious like honesty and responsibility, but there are other values too, like having fun. That's the thing that really struck me was having a value of having fun, which is just as important as honesty and responsibility."

Strategies to Empower Participants

Participants employ the empowerment that they acquire at the Oaks to engage in three strategies that lead to enhanced capabilities. These strategies include reducing stigma, maintaining employment, and improving living conditions. Evidence confirming our claims are presented below.

Reducing stigma

Participants at the center employ a variety of coping strategies (e.g., trying to educate others on mental illness) in some form, but as they become more empowered to make their own decisions, they draw strength from these experiences and actively take steps to reduce stigma aimed at themselves and other mentally ill persons as illustrated in a conversation with Jean-Marc.

Jean Marc: Schizophrenia... see how it is for them. [Many] don't understand mental illness. You've got to tell them.

Interviewer: You've got to educate people?

Jean-Marc: Yeah. Let them know.

Another way that participants actively reduce stigma is to participate in NAMI

connection groups and events. NAMI is a national organization that advocates, educates, and leads events to “fight stigma and encourage understanding” (NAMI 2017). The Oaks hosts a NAMI connection group every Thursday afternoon and the members often walked together in the citywide NAMI walk. Grace, a 27-year-old white female with a “touch of bipolar” said that she and other participants, “go on walks like when they have the 5K walks with NAMI and Hunger Walk.” When asked if participating in the center helped him acquire any new skills, Andy referred to NAMI and other connection groups saying that participation “got [his] mind right.”

When asked

Getting his “mind right” resulted in his re-engaging with family members in the community, which allowed him personhood in the community where he could talk about his experiences.

Maintaining employment

Two of the programs at the Oaks are income-producing for participants: gardening and art therapy. According to James, a former staff member, gardening in particular has monetary advantages.

A lot of the gardeners probably make between 60 and 80 dollars a month, which by free market standards is not a lot of money at all, but if you only get 700 dollars a month in Social Security and you’re paying 650 of that to personal care home, with really [shoddy] accommodations, the difference between all that you have left was 650 of 700, that 50 dollars plus another 80 all the sudden makes big, big difference, access to recreation, [and] opportunities to do something outside the house.

There are also other opportunities to earn income at the center. Will does

“janitorial work... I wipe down tables... I sweep and mop the floor... I stand the chairs on top of the tables... I... take out the trash.” One participant, Alex, participant turned staff member has become the center certified nursing assistant at the Oaks. He originally arrived at the center resulting from a court order to attend a day program after an incident involving violence against his mother. He began telling the staff members about his former occupation:

They thought I was delusional saying that I was a nurse, come to find out I was [a nurse]. Yeah, it was an experiment [to practice nursing at the center] and I volunteered for a year doing what I do now...[and] I basically built the program from the ground up over there.

Improving living arrangements

Most participants attending the Oaks live in unlicensed personal care homes in the area surrounding the center. A common theme among participants was the desire to live independently one day. For most, this will never be a reality, but there is the opportunity to improve current living arrangements. Mike shared a story about a staff member helping with a move to a better situation, primarily flexibility and opportunities to leave the personal care home during the day and walk the neighborhood and visit neighboring businesses:

Just recently Susie (a staff member) got me help... to live over there (in a nicer personal care home). She gave me a lady's name and phone number, Miss Eileen, and I moved in. So she helped me find a place.

A couple of participants have even graduated from personal care homes to more independent settings with only three other roommates. Grace said:

When I first started coming to the program, I was in a personal care home. After a while of being in a personal care home, I met Ross here. Ross helped me get out of that personal care home and

into the house— a house that is ran by one of the volunteer staff that works here. If I did not have this place, I would not have as many connections as I have through the Oaks.

Since the time of the interview, Grace left the home run by the volunteer staff person and now lives independently. As evidenced by these quotes, through involvement in the program and engagement with other staff members, participants were able to find improved living situations (i.e., licensed personal care homes, independent living with fewer roommates, and, for a small few, independent living).

Enhancing Capabilities

There are ten central capabilities outlined by Nussbaum (2011) and findings show that four of those capabilities are cultivated and supported by the Oaks, including *control over one's life*, *emotions*, *affiliations*, and *play*. Below, these capabilities are described in detail and the claims are supported through field notes and interviews with staff and program participants.

Control over one's life

As previously stated, the opportunity to engage in income producing work is empowering and leads to enhanced capabilities. One of the central capabilities defined by Nussbaum is “being able to work as a human being, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers.” We refer to this capability as *control over one's life*, which maps directly to the strategies employed by participants. This sense of control or autonomy, which is shown in the literature to improve mental health outcomes is evident in the following excerpt from field notes.

Marshall works in the garden. He said he got involved with gardening by simply asking if they needed any volunteers. [The gardening] director said yes, [he could work in the garden]. Because Marshall is working in the garden now, he says that he does talk about the center and working in the garden [whereas he did not before. He] tells [his mother] that ‘things are going well’ and that it’s “pretty nice place” [to attend and work].

Gaining employment at the center and maintaining the employment has elevated the status of Aaron, an African American male diagnosed with schizophrenia, originally attended the Oaks as a participant. This excerpt from field notes describes a discussion the first author had with Aaron that illustrates this point.

I asked [if he] worked [before as a] janitor and how he [came about getting] the job. He said that he started coming to the Oaks as a participant but it wasn’t long before Father Scott (a former vicar) had him doing some janitorial work around the place. He works about 15-20 hours a week now. [When Aaron first started coming to the Oaks,] he was living in a group home. I asked if he lives independently [now] and he said he does.

This autonomy that Aaron had in his work life resulted in his moving out of a group home and finding, and subsequently marrying, someone. He even got a dog, he named Pepper, which represents a freedom and choice that is not afforded to a participant living in a group home. The opportunities given to him, attachments to another person and independent living, grew to large part out of the confidence he gained from having meaningful employment at the Oaks.

Emotions

One of most evident ways that participants are “able to have attachments to things and people outside of ourselves,” (the definition of Nussbaum’s capability of *emotion*) is through community meetings held once a quarter in the sanctuary of St. Francis and led by the former Executive Director, James. In these

community meetings, participants think of themselves as part of a “larger thing” (coined earlier by James), which encourages them to have a vested interest in the community. In field notes, the first author wrote about the community meeting:

I go to the Sanctuary for the community meeting. Everyone is strongly encouraged to attend, which means that everyone is there. James opens the meeting up by asking people what they would like in a new Executive Director position. The following words come up: cooperative, observe the community first, respect boundaries, set up expectations, voice in the search process, more small group activities, strong performance, honest, social support, has a mental illness- compassion/empathy, continuation of programming and growth of that programming, for the ED to stay healthy, and they want a balance of someone doing admin work and being hands on.

Later that day when James was informally interviewed, he spoke about value of community meetings in articulating core beliefs of the Oaks’ community. This articulation allows participants to think beyond their personal needs and wants and corporately create core values of the Oaks. James said:

The community members said let’s throw out [the previous core values developed by the vestry at St. Francis] and start over again and we did a brainstorming session where the community is now saying these are our core values which is where we came up with well-being, inherent value of self, diversity.

Affiliation

A core central capability is affiliation or “being able to live with and towards others, to engage in various forms of social interaction.” Most individuals in the general population take this capability for granted as it is a natural extension of themselves, but for this disenfranchised and marginal group, they have limited experience with social interactions, much less building relationships with others like themselves.

At the center, participants have the opportunity to develop fulfilling relationships with other participants. Sometimes, the conversation is basic and on the surface seems to be about an inane topic, for example in a conversation recorded between Ronnie and Johnny in field notes, both elderly African American men with schizophrenia:

Ronnie says, "Where you get that candy at?" Johnny replies, "My sister." Ronnie says, "When your sister come and bring you candy?" Johnny replies, "This weekend." This may not sound like a lot of conversation, but it really stands out as being conversational. Johnny never asks Ronnie for candy, he asks out of curiosity [about Ronnie's life].

What this excerpt represents is a level of interest in one another and the attempt to build a bond with another person. Another example of this showing of interest is evident in the following field note excerpt:

I try to introduce [Roger and Stuart], but just after they told me that they didn't know each other, they say they do [know each other] and have for years. They talk briefly about what other programs they've been to and it forms some sort of common bond.

Occasionally, a participant will talk about a preference to befriend another participant or staff member, but this talk is rare. Tom, a white middle-aged man who was recently diagnosed with bipolar disorder and had suffered from drug and relationship addiction, said about his friendships at the Oaks:

I tend to gravitate toward women [at the center] for friendships and I've made several - you know like, three or four. Like, there's a gay couple [on staff at the center] and I'm gay and that makes me feel really comfortable.

Social interactions sometimes serve a different purpose, they serve as a calming effect for participants who are at the mercy of the negative symptoms of their mental illness. Their natural inclination and history with a mental illness has

marginalized them from others; reaching out for help to calm down is difficult.

The staff recognizes this and either explicitly or implicitly encourage participants who are in the midst of heightened emotions. Two examples from observations of this encouragement are presented below:

Will came in[to the office] and said that he would not be working his janitorial duties at the art center today because he didn't trust himself not to get in a fight with someone. It was also the reason that he did not D.J. the Halloween party. He said he wanted to leave, but Leon [the kitchen manager] encouraged him to stay in the office and be around people who understood what he was experiencing until he felt calm enough to leave.

While [Chelsea and I] are in [the office] Grace comes in wanting to use the computer...she just wants to interject herself into a social interaction.

Play

Nussbaum defines the central capability of play as “being able to laugh, to play, to enjoy recreational activities.” For many participants, they do not have the material resources to participate in recreational activities that may bring them enjoyment. The Oaks provides an environment where participants can laugh and engage in activities. Terry, a formerly incarcerated African American male, indicates that he craves activities that bring enjoyment:

I need something that's fun... I'm kind of like, spontaneous... like, I need stuff that's interesting that'll keep my attention.

When probed further about what would keep Terry interested, he said, “the painting... something I can be creative.” The art therapy program is very popular among participants and allows them to enjoy a recreational activity that they would not otherwise have the opportunity to participate in outside the Oaks. Luis, a forty-five year old schizophrenic, echoed Terry about enjoying art and how he

can choose the medium of art he engages in at the center, “I try to draw birdhouses... some kind of tree houses.”

Some of the recreational activities are highly structured, like art therapy, bingo, and yoga, but some activities are less structured. For example, the Oaks celebrates holidays by incorporating participants into the planning and hosting of the events. These events are meant to be fun and they typically capture the attention of everyone, including the “smokers” who do not usually participate in organized activities. An example of this is, as recorded in field notes, is a Halloween party when participants made costumes and the staff threw a party:

Abigail [the art director] is...making costumes and masks for people for the Halloween party that will start after the staff meeting... When I arrived first thing that morning Madeline was bagging five pieces of candy per zip lock to make a total of eighty [bags for the participants]. James [the Executive Director] asked me to bag the rest of the candy and he put them in shopping bags to take downstairs to the common room where Will was going to act as a D.J. for thirty minutes while [the researcher and staff] handed out candy and people put on costumes and wigs to get in the spirit of Halloween... Will was wearing a purple wig in a bob and Abigail was cutting out fabric to make masks and ponchos [for other people]. Alec was wearing an orange mask and poncho made out of orange felt, which made him look like a pumpkin. It was cute and playful.

Sometimes, the activities are not for special occasions, like the Halloween party, but just as a nice treat offered by volunteers who are personally invested in creating a positive experience for participants. One day, Rochelle, a volunteer who is currently unemployed and has bipolar disorder, brought donuts to the participants who live in the Roswell House because she picks them up on the van route every program day. In field notes, the first author wrote, “We [myself, the researcher, volunteers, and participants] are all equals, just sitting around at 8:30

in the morning eating donuts.” That is what the recreational activities provide for the participants, staff, and volunteers -- a sense of equality that allows everyone to enjoy each other.

Many participants feel a deep connection to the Oaks, which allows them a sense of belonging to a social group that fosters empowerment. Through this newfound agency, participants actively reduce stigma, improve living conditions, and some even maintain income-producing employment. These strategies allow them to have enhanced capabilities that include increased quality of life through autonomy, community, social interactions, and recreational activities. However, not all participants are able to reach toward enhanced capabilities due to symptoms of their mental illness (e.g., recurrent hallucinations), cognitive limitations, or substance misuse or abuse.

DISCUSSION

The purpose of this study was to determine if this organization that we refer to as a mediating structure provides a sense of belonging to a group of marginalized chronically mentally ill adults and whether this sense of belonging resulted in increasing empowerment that lead to enhanced capabilities. The benefit of the Oaks is that it provides a sense of belonging, most commonly in the form of “connection,” a hopeful experience for people living with chronic mental illnesses who do not commonly feel any connection to conventional others (i.e., other individuals and institutions). This connection did empower participants to try to reduce stigma, maintain or improve their living arrangements, and increase employment opportunities. While participants did not explicitly indicate an

understanding that they belonged to the Oaks, they implicitly communicated this concept through both their confessed enjoyment of the center and concern over what might happen should the center close.

The concept of mediating structures applies to this population, but in a modified version, while the capabilities approach is extended to a vulnerable and marginalized population within a highly developed nation. The original form of mediating structures (Berger & Neuhaus, 1977) indicates that individuals feel a sense of belonging to organizations, thus becoming empowered to make public policy changes in their communities and beyond. This application is not well-suited to vulnerable and marginalized populations, such as the chronically mentally ill, who lack personal empowerment to the same extent as the general population. While experiencing empowerment to positively change their lives in some capacities (i.e., reducing stigma, improving living arrangements, and maintaining employment), individually they are unable to effect policy changes on a broad scale. However, they are invited to participate in community meetings, whereby they have a voice that is taken into account by staff who advocate for them within a larger context (i.e., in both the Episcopal diocese and the community). Through the empowerment that they are able to acquire, they develop enhanced capabilities to strengthen engagement in communities and relationships with others reaching their maximum potential.

This qualitative study not only extends the theory of mediating structures, but it also employs the capabilities approach (Nussbaum, 2011) to explain how participants can flourish in this particular setting. Although perhaps not explicitly,

the staff at the Oaks regularly asks the central question of this approach—“what are people actually able to do and to be?” (Nussbaum, 2011:X). The answer is that many participants are able to make friends, join in activities they enjoy, and some are able to engage in income-producing work, such as gardening and art therapy. Participants are also capable of self-directing their recovery, working toward reducing stigma, and working toward improving their living conditions. Knowing that these outcomes are possible for many, the staff then ask: “How can we get as many participants to the place of agency where they control the quality of their lives?” This is when programmatic efforts take shape and “loitering with intent” becomes a critical element of the organization’s mission.

The capabilities approach also strives to empower individuals to make choices and plan their futures. This is a tremendously hopeful advancement for many mentally ill individuals who have languished for a majority of their lives before attending the center. We find that four central capabilities identified by Nussbaum (2011) apply to this successful group of participants, *control over one’s life*, or “being able to work as a human being, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers” (Nussbaum 2011:34). This in addition to include *emotions*, or “being able to have attachments to things and people outside of ourselves,” *affiliation*, or “being able to live with and towards others, to engage in various forms of social interaction, and *play*, “or being able to laugh, to play, to enjoy recreational activities” (Nussbaum 2011: 34). They have been passive beings, allowing others to make their health decisions, manage their financial resources, and plan their

futures, which for many are rather bleak. The process of empowering individuals through their sense of belonging at the center changes the status quo for many who attend the Oaks.

While the notion of moving people to their full potential works for many of the participants at the Oaks, it is important to note that some participants are never able to acquire the agency necessary to make significant changes in their own lives. The marginalization they experience due to their symptoms of mental illness is simply too powerful to overcome. The Oaks recognizes that some of their participants feel a sense of belonging and that is a sufficient benefit. Any movement toward stability, meaning, and friendship is positive. In terms of the capabilities approach, for these lower functioning individuals, they can be and are part of a meaningful community, and that experience in their lives is limited to this social setting.

Although this study provides insights regarding an understudied and vulnerable population, several limitations should be noted. This research project consists of a small, purposive sample of participants engaged in a day program in a major metropolitan area. The interview sample was biased toward those who played a central role in the social life at the center and who were able and willing to be interviewed; it may not reflect the perspectives of those who did not want to be interviewed. We acquired some participants' perspectives from informal interviews and observations in the cases of those who did not want to be interviewed. Another group we had limited interaction with were those who had difficulty communicating verbally.

CONCLUSION

In sum, this paper contributes to the literature by extending the concepts of mediating structures and the capabilities approach to a vulnerable and marginalized population in the southeastern United States. New insights from this study have practical and policy implications. Practically, it addresses the need to consider the actual experiences of this population in order to understand and measure “positive outcomes.” The structure and function of the Oaks continues to be a successful model for empowering chronically mentally ill adults. Future policies should focus efforts and resources to developing programs that enhance the capabilities of chronically mentally ill individuals.

REFERENCES

- Berger, P. L. (1976). In praise of particularity: The concept of mediating Structures. *The Review of Politics* 38(3):399-410.
- Berger, P. L., & Neuhaus, R.J. (1977). *To empower people: The role of mediating structures in public policy*. Washington, D.C.: American Enterprise Institute for Public Policy Research.
- Bopp, M., & Fallon, E.A. (2013). Health and wellness programming in faith-based organizations: A description of a nationwide sample. *Health and Promotion Practice* 14(1):122-131.
- Boykin C., Lolita, & Thomson, G.J. (2007). Caregivers/faith-based organization

coalitions: An innovative model for mental health caregiving. Paper presented at the North American Association of Christians in Social Work, March 2007, Dallas, TX.

Charmaz, K. (2014). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage Publications Inc.

Corbin, J., & Strauss, A. (2015). *Basics of qualitative research: Techniques and procedures for developing grounded theory 4ed*. Thousand Oaks, CA: Sage Publications Inc.

Dossett, E., Fuentes, S., Klap, R., & Wells, K. (2005). Obstacles and opportunities in providing mental health services through a faith based network in Los Angeles. *Psychiatric Services* 56(2):206-208.

Durkheim, E. (1951). *Suicide: A study in sociology*. Glencoe, IL: Free Press.

Grosby, S. (2010). Peter Berger's contribution to the pluralism of mediating structures. *Society* 47(3):193-199

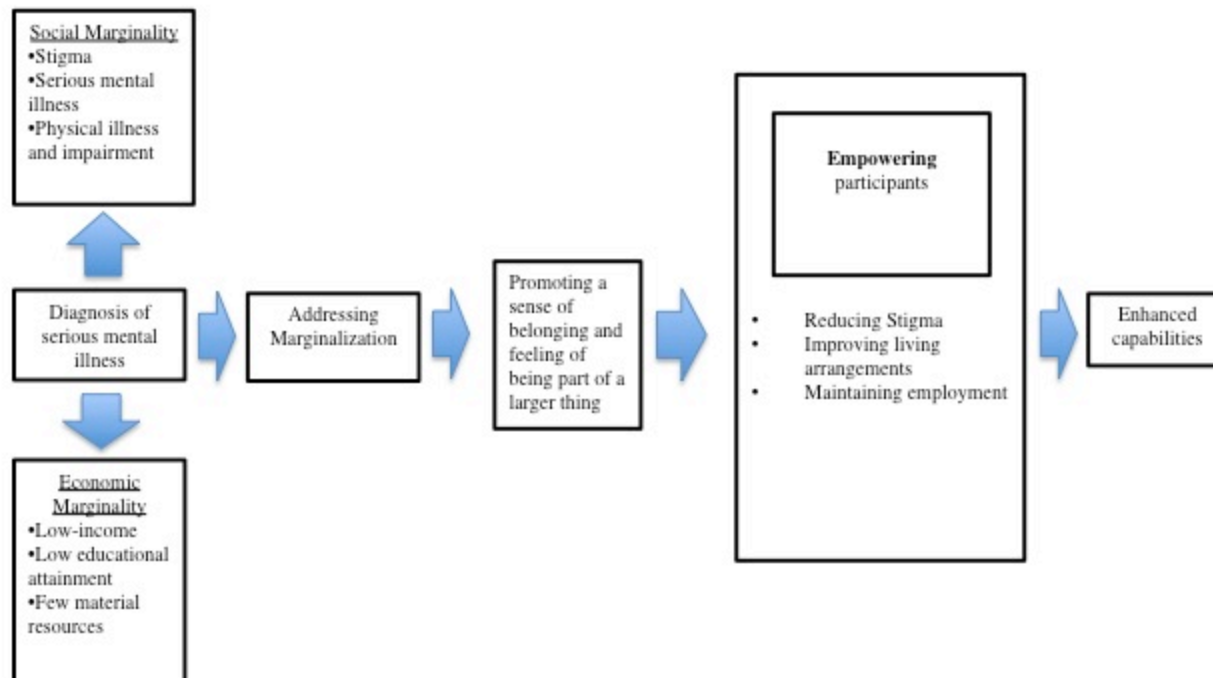
Kerrine, T. M., & Neuhaus, R.J. (1979). Mediating structures: A paradigm for demographic pluralism. *Annals of the American Academy of Political and Social Science* 446:10-18.

Leavey, G., Loewenthal, K., & King, M. (2007). Challenges to sanctuary: The clergy as a resource for mental health care in the community." *Social Science & Medicine* 65(3):548-559.

Levin, L.S., & Idler, E.L. (1981). *The hidden health care system: Mediating structures and medicine*. Cambridge, MA: Ballinger Publishing Company.

- Mendel, S. (2003). The ecology of games between public policy and private action: Nonprofit community organizations as bridging and mediating institutions. *Nonprofit Management & Leadership* 13(3):229-236.
- Mersereau, B. (1997). *Off the street: The story of friendship centers*. 2nd ed.
- Sider, R., & Unruh, H. (1999). Saving souls, saving society: Exploring the spiritual and social dynamics of church-based community activism. Unpublished manuscript.
- Walker, R. (1992). Inter-organizational linkages as mediating structures in community health. *Health Promotion International* 7(4):257-265.

FIGURE 2.1 Conceptual Model : A model to increase enhanced capabilities



CHAPTER 3

SOCIAL RELATIONSHIPS OF THE CHRONICALLY MENTALLY ILL IN THE CONTEXT OF A FAITH-BASED DAY PROGRAM

ABSTRACT

Existing literature on the social relationships of the chronically mentally ill consists primarily of studies conducted shortly after deinstitutionalization; much of this research presents the chronically mentally ill as lacking the ability to develop meaningful relationships. The purpose of this grounded theory study was to investigate and build on earlier findings. All fieldwork was conducted from 2012-2015 at a church-sponsored community-based day program in a major metropolitan area serving a racially diverse group living with chronic mental illness. In contrast to earlier work, the current study shows that members of this disenfranchised group have multiple, complex relationships and find meaning and a sense of empowerment through a process of relationship building that we have labeled “maximizing choice in relationships.” Findings have important implications for developing interventions that can reduce the social marginalization of this vulnerable population and increase their community engagement.

KEYWORDS

grounded theory, mentally ill, social support, convoy model, aging, Atlanta

INTRODUCTION

In the United States in the 21st century, most people with a chronic mental illness live in the community. Within the community, they must continually navigate between their often unstable group living arrangements, the mental health care system, and therapeutic day programs (Perkins, Ball, Whittington, & Combs, 2004; Perkins, Ball Whittington, & Hollingsworth, 2012). Prior to the mid-twentieth century, those deemed incapable of living independently typically were not housed in the community and instead were locked away from society in insane asylums, or total institutions. In the 1960s, deinstitutionalization, the movement of psychiatric patients from the total institution into the community, peaked, with a 65% reduction in institutionalized patients within ten years (Mechanic and Rochefort, 1990; Powers 2017). In the years following

this social reform, concerns of advocacy groups and policymakers centered on helping the chronically mentally ill find housing and employment, as well as building social skills, strategies shown to protect against poor mental health outcomes (Powers 2017). Unfortunately, despite these strategies, the chronically mentally ill, especially those living in poverty, continue to experience stigma related to their illness and low socioeconomic status, and often are marginal to their communities (Ball et al., 2005; Perkins et al., 2004).

Changes in policy related to deinstitutionalization that took place across the country also occurred in Georgia, the setting of the current study. Thirty years after deinstitutionalization, the 1996 Olympics were held in Atlanta; a large-scale effort was undertaken to clean up the city, including moving the chronically mentally ill -- many of whom were homeless -- off the streets and into psychiatric hospitals or they were given one-way bus tickets out of town. These tactics did not completely solve the problem, so the city collaborated with six city churches to open day programs for the explicit purpose of keeping the chronically mentally ill off the streets during the period for the duration of the Olympics. When the games ended, most of those centers closed because funding ended. However, one faith-based program continues to operate, providing support and services to this vulnerable and marginalized population. This study focuses on the social relationships of participants in this program. A key focus is on the types of relationships participants develop with one another. Building on earlier scholarship in this area (Estroff 1971; Estroff, 1981; Rosenfield & Wenzel, 1997; Wong, Matejkowski, & Lee, 2011; Yanos, et al., 2001), the following research questions guide the study: (1) What are the characteristics of participants' social support networks and how do these properties vary

with regard to the inclusion or exclusion of fellow program participants?; (2) How do participants define their relationships with other program participants?; and (3) What factors shape participants' relationships with other program participants?

BACKGROUND AND THEORETICAL CONTEXT

Earlier Studies on Social Relationships among the Chronically Mentally Ill

In the early 1980s, Estroff (1981) published a landmark ethnography exploring the experiences of the chronically mentally ill living in the community after deinstitutionalization. This study, which was conducted in context of a community treatment program similar to that of the current study (although it was not a faith-based program), provides in-depth information on the social relationships of the chronically mentally ill at the time. Her initial research aim was to gain a general understanding of the lives and activities of the chronically mentally ill, but as data collection continued, her research concentrated on some specific topic areas, including social relationships. In examining social relationships, Estroff discovered that the mentally ill “chose to act primarily with each other” (1981:249) because they preferred interactions with other mentally ill people who shared similar lived experiences. A contributing factor supporting this finding included the “perception of common differences...and [participants] lack of relationships with [the non-mentally ill]” (Estroff 1981:230). Although she recorded detailed observations regarding relationships in addition to a number of other aspects of participants' lives, Estroff admits she still lacked a comprehensive understanding of relationships among clients. She writes, “We know very little about the friendships among clients, their social and interpersonal networks, and the impacts these have on their lives and treatment” (Estroff 1981:187).

Later studies show that chronically mentally ill persons receive social support from a variety of sources, including family (Ohaeri, 1998), friends (Forrester-Jones, et al., 2012), religious supports (Nguyen, et al., 2012), and even the wider community (Stockdale, et al., 2007). Some of these findings, however, indicate that these individuals are still most likely to engage in social relationships with others with mental illness, probably due to a lower perceived risk of social stigma present in these interactions (Rosenfield & Wenzel, 1997; Wong, Matejkowski, & Lee, 2011; Yanos, et al., 2001). Some studies show that the chronically mentally ill frequently have a history of negative relationships with their families (Sapin, Widmer, & Iglesias, 2016), a problem which can affect their ability to form other types of relationships, including relationships with other mentally ill individuals (Rosenfield & Wenzel, 1997; Yanos, et al., 2001).

Positive and Negative Aspects of Social Relationships

Social relationships include both positive and negative aspects (Darbonne, Uchino, & Ong, 2013). Social relationships are protective against the onset or exacerbation of psychiatric illness (Lin, et al., 1979; Saha, et al.; 2012, Strine, et al., 2008) and are advantageous in maintaining psychological well-being as well as decreasing symptoms of depression and anxiety (Agtarap, et al., 2017; Kawachi & Berkman, 2001). Negative interactions are reported less often than positive ones, but are still influential. Not surprisingly, social negativity is associated with lower life satisfaction (Darbonne, et al., 2013; Yanos, et al., 2001). This topic has been investigated for the general population and also for the subpopulations of chronically mental ill adults attending a social club (Yanos, et al., 2001) and among mentally ill mothers involved in custody battles (Hollingsworth, Swick, & Choi, 2013), but not yet for the vulnerable and

marginalized population of aging mentally ill adults. The social relationships of the aging mentally ill possess unique properties and need to be studied in a particular context; the social convoy model provides the context to accurately measure those properties.

The Social Convoy Model

The social convoy model refers to the protective layer of family and friends who surround the individual throughout the life course (Kahn & Antonucci, 1980; Levitt, Weber, & Guacci, 1993; Peek & Lin, 1999). According to the social convoy model, relationships are arranged hierarchically as very close, somewhat close, and less close. In accordance with this model, the number and degrees of closeness within relationships are posited to be predictors of well-being.

While relationships with some convoy members may be lost over time, some members may join the convoy late in life, particularly in times of need (Perkins, et al., 2013). Losses to the convoy result from “life course transitions, such as retirement, relocation, and the loss of a spouse or other close ties, [which] mean that older adults generally have smaller, less active, and less diverse networks compared with younger adults” (Perkins et al. 2013:497). Smaller networks may be a trend, but some older adults have large diverse networks, which decrease their risk for depressive symptomology (Antonucci, Fuhrer, and Dartigues, 1997).

The social convoy model consists of four key constructs that describe the processes, characteristics, and mechanisms through which social relationships influence health outcomes. These constructs include quality, closeness, structure, and function (Antonucci et al., 2014). Quality is typically measured by one’s level of satisfaction with the relationship. Closeness is often measured based on perceived degree of closeness of

relationships. Structure refers to size and composition of one's social support network. Lastly, function refers to types and adequacy of social support given and received among network members. This study is the first known study to use this framework to investigate social network characteristics of low-income individuals with chronic mental illness.

METHODS

Research Design and Approach

To address study aims, this research uses qualitative methods (participant observation, in-depth and informal interviews, and review of program records) to study the lives of the chronically mentally ill located in a faith-based day program in the metropolitan Atlanta area. After approval from the Emory Institutional Review Board, data collection and analysis began in 2012 and ended in 2015. The research is guided by grounded theory methods (GTM). GTM is used to construct theory through a constant comparative method whereby data collection, hypothesis generation, and analysis are conducted simultaneously (Charmaz, 2014; Corbin & Strauss, 2015). A goal of GTM is to gather “thick description” and construct empirically grounded theory that captures the lived experience of study participants (Charmaz, 2014; Corbin & Strauss, 2015). The flexibility of this approach to address new findings and modify assumptions made *a priori* allowed us to maximize the exploratory nature of the study—an important strength when pursuing new areas of research.

Study Setting and Population

The Oaks² is a church-sponsored community-based day program located in an urban neighborhood within the city of Atlanta. The program has no formal membership process and anyone over the age of 18 is eligible to participate. The Oaks is held at the St. Francis church, which also holds services on Wednesday nights and Sunday mornings. Participants who attend the day program comprise the majority of the church congregation, and serve as greeters, acolytes, and readers of the liturgy. This combination of a familiar population with expanded opportunities for social fellowship creates a hybrid community that both welcomes and enriches the lives of participants.

Volunteers drive church vans to surrounding neighborhoods to pick up participants in the morning. Various staff members greet participants as they exit the vans in the morning. Breakfast and coffee are served between 9-10am. Many participants move to the smoking section following breakfast while others hang out in the fellowship hall chatting or coloring or sleeping. At 10:30am, therapy programs, including art and yoga, and gardening work begin. About two-thirds of participants engage in these programs. At 12pm, participants start lining up outside the door to the fellowship hall for lunch. Following lunch, participants line up for the vans that take them back to their group homes. On average, about 60-70 people attend a program day, but not all the same people attend every day. The reasons for this variation include illness, hospitalizations, incarcerations, and moves outside of the van routes.

Program participants are socioeconomically disadvantaged. More than 30% of program participants have been homeless at some point in their lives. Many are Supplemental Security Income (SSI) recipients and are living below the federal poverty

² All names are pseudonyms

level, which is \$11,770 for a single resident household (Department of Health and Human Services 2016). The majority of participants live in private, for-profit small low-income personal care homes, often referred to as group homes or board and care homes, both licensed and unlicensed, that address very basic needs for food and housing. A small number of participants live alone in low-income independent housing and receive oversight from a social worker, or live with family.

Data Collection

Primary data collection at the Oaks included participant observation, informal interviews, semi-structured interviews, and review of archival program data and marketing materials. Over a period of 41 months, the first author conducted 38 site visits and logged a total of 81 hours of fieldwork. The first author conducted 27 in-depth interviews with program participants and seven with key program staff. All data were gathered at the main campus and at the art center during program hours. Additional observations were made on the van rides between the program participants' homes and the center. Interviews were conducted in the library and the nursery on the church campus. In-depth interviews lasted between 30 to 60 minutes, with an average time of 40 minutes. All interviews were digitally recorded and transcribed verbatim by the first author. We used a qualitative software program, NVIVO11, to facilitate storage, management, and coding of all qualitative data.

Participant observation. As a participant observer, the first author actively engaged in social interactions and informal conversations during both fellowship and programming. Activities the first author engaged in with participants included Bingo, art therapy, yoga, Bible study, gardening, and meals. During field visits, three types of notes

were recorded: observational, methodological, and theoretical or analytical (Muller, 1995). Observational notes included physical descriptions of program participants and the research site, as well as detailed accounts of informal conversations, events, interactions and behavior. Methodological notes informed fieldwork strategies and included documentation of any methodological problems that were encountered, including challenges with recruitment or problems related to the research instruments that needed to be addressed. Theoretical notes included questions we had about the data and ideas for future observations (i.e., theoretical sampling) (Corbin & Strauss, 2015).

Semi-structured in-depth interviews. Interviews were conducted with all program participants who were willing to be interviewed and had the cognitive ability and communication skills to participate in a formal interview. As the study progressed, theoretical sampling was used to gain additional information from interview participants and others through informal interviews and observations. Several interview respondents in the study typically spent most of the program day engaged in unstructured activities, such as sitting in the smoking section or hanging out with other participants. These participants were easier to access and enroll for interviews compared with others engaged in potential income producing work (i.e., gardening or art therapy) or bingo. Twenty-eight participants were asked to participate in in-depth interviews and 27 agreed. The one participant who declined stated lack of interest as a reason.

Social network mapping. As part of the in-depth interview, we utilized Antonucci's (1986) hierarchical network mapping technique (see Appendix A) to identify characteristics of participants' social support networks. A diagram was presented consisting of three concentric circles; participants were then asked a series of questions to

determine the size, composition, and nature of their social networks. For the inner circle, participants were asked to list people with whom they were so close to that they couldn't imagine living without them. Next, the first author asked participants to list in the middle circle people who they were close to, but were not as close to as the inner circle. For the outer circle, the first author asked participants to list people they were somewhat close to, but had not yet mentioned, yet still wanted to include in their networks. Following the initial listing of people in the social network map and again in the concluding question section, participants were asked: "Is there anyone else you would like to add to your circles?" Most commonly, participants said they had already listed everyone they wanted to list. Additionally, if there were other specific individual(s) with whom the first author had previously observed a participant socially interact with at the center, she would ask why that person was not listed. Sometimes participants would say, "I don't want to add anyone." In a few instances participants said, "Yeah, you can add [participant's name]." While this approach served as a validity check, it may have biased the size of the networks upward.

Following the questions regarding closeness, the first author asked a series of questions about the people listed in the social network map. She first had the participant report the gender and race of each network member. Next, she asked specific questions regarding the history and nature of each social relationship the participant listed. These subsequent questions included: "What is your relationship with the person you listed?" "How long have you known this person?" "Where did you meet this person?" "How often do you speak to the person?" "Does this communication usually take place face-to-

face or by phone?” I then asked participants to tell me how long it had been since they had spoken to the person.

Facial expression chart. In addition to measuring social support networks, interview participants were asked to rate the quality of their social relationships with the members listed in their social network map. A facial expression chart created by Andrews and Withey (1976) was used. Facial expressions ranged from 7 (very happy) to 1 (very sad or angry). Participants pointed to the facial expression that most represented how they felt about each network member. In some instances, additional questioning was needed due to the length of time since their last interaction. In those cases, participants were asked, “How did this person make you feel the last time you spoke to him/her?”

Data Analysis

Analysis involved two grounded theory procedures: coding and “theoretical memoing.” Coding is the identification and naming of themes and categories. In GTM, coding includes three stages: open coding, axial coding, and selective coding. *Open coding* is the breaking apart of raw data, identifying initial concepts, and defining these in terms of their properties and dimensions. In *axial coding*, the researcher links categories and subcategories in terms of a *paradigm model* denoting causal conditions, contexts, intervening conditions, action/interaction, strategies, and consequences (Corbin & Strauss, 2015). In *selective coding*, the researcher identifies a central theme or core category that links all other categories and their relationships and develops the final storyline denoting these connections (Creswell, 2012). Analysis is considered complete when theoretical saturation occurs. Theoretical memoing reflects the thoughts and insights of the researcher while engaged in the process of data collection and analysis

(Corbin & Strauss, 2015; Charmaz, 2014). Theoretical or analytical memos include detailed narratives or storylines as well as diagrams, matrices, and charts. In this study, memos were dated and provided an audit trail and detailed record of theory development. This audit trail of dated memos and field notes recorded throughout all stages of data collection served to guide theory development as well as to help identify and address potential researcher bias. Other strategies we used to establish credibility of the analysis included prolonged engagement and persistent observation, triangulation through use of multiple data sources and data collection methods and multiple analysts, negative case analysis (searching for cases that disconfirm or contradict major categories and patterns identified in the data), and member checking (seeking feedback from study participants regarding findings and interpretations). Analysis was consistently reviewed and informed through regular meetings with the co-authors.

To inform the grounded theory analyses and provide context for these findings, we used descriptive statistics to summarize the characteristics of participants' social networks and to describe the quality of these relationships (i.e., based on the facial expression chart).

RESULTS

Demographics

Table 3.1 shows descriptive statistics of the sub-population of Oaks participants who were interviewed. Most participants in this sample were male (82%) and African American (71%). The average age was about 49. Most participants had low educational attainment as evidenced by the number of participants who had less than a high school education (44%) or were high school graduates (30%).

Insert Table 3.1 about here

Characteristics of Participants' Social Networks

The range, means, and standard deviations (SD) of participants' social networks are presented in Table 3.2. The average number of network members listed by participants was about 8 with a range of 0-19. Most participants (93%) listed at least one family member in their inner circle (Mean=2.89, SD=2.33). Only 19% of participants listed a family member in their middle circle (Mean=.30, SD=.67) and 11% of participants (Mean=.19, SD=.56) listed family in their outer circle. Participants were more likely to list other participants at the Oaks in their middle circle (range 0-10, SD=1.99) and outer circle (range 0-10, SD=2.24) than in their inner circle, indicating a moderate level of emotional closeness. The ranges for these corresponding circles are positively skewed by two participants, one of whom listed "everybody at the Oaks" in his middle circle and another who listed "everyone here" for the outer circle. Staff/volunteers were not mentioned by very many participants; the range was 0-1 in the inner and outer circle and 0-4 for the middle circle. The corresponding means and standard deviations for the inner circle are (Mean=.08, SD=.27), the middle circle are (Mean=.33, SD=.88), and the outer circle are (Mean=.15, SD=.36). These descriptive statistics indicate a lack of closeness to staff/volunteers.

Table 3.2 also shows the percentage of participants with at least one tie in each category. Ninety-three percent of participants included at least one family tie in their inner circles. Participants were more likely to list other program participants in their middle circle (33%), although close to one-third listed other participants in their outer

circle (29%) and a quarter (25%) listed other participants in their inner circle. Overall, participants included few staff members/volunteers in their social network maps.

Insert Table 3.2 about here

Findings show that it was more common for participants to list family in the social network map than it was to list any other type of social tie. This finding is consistent with other studies conducted among socially marginalized individuals in a group setting (Perkins et al., 2013) and likely derives from participants' desire to have social relationships consistent with societal norms.

Close to half (41%) of participants did not list any other program participants from the Center in their network. Even though participants had ample opportunity to foster and maintain relationships with fellow participants, they often did not list them. This absence of program participants in the social network map was at odds with observations that showed that participants had multiple and varied relationships with other participants.

With regard to staff and volunteers, findings showed some notable changes in relationships that occurred over time. In early interviews, for example, some participants listed both the Executive Director and Vicar in their social network map. Following the departure of these staff members, only a couple of people listed the new Vicar, Chelsea, who was also serving as the Interim Executive Director of the Oaks. While the new Vicar was clearly dedicated to the needs of the entire congregation, she was not as visible in the daily life of the center as the previous Vicar and Executive Director had been. This lack of visibility combined with her gender and what Chelsea referred to as her own

“anotherness” delayed rapport building. Chelsea described the interaction she had with Ernie, a participant who did not approve of having women in the priesthood:

Ernie said, “Well we don’t get along very well.” And I said, “What are you talking about? I think we get along just fine.” He said, “Well, it’s a personality clash.” And I said, “You don’t like me?” And he said, “No, I don’t like you. Women aren’t supposed to be priests.”

Chelsea believed that being a priest was a key factor related to her “anotherness.” She said, “The collar is a barrier between me and other people no matter what I do or where I go . . . There is an anotherness to me that I can’t stop.”

Another notable finding was that participants rarely listed people in their outer circle (Mean=1.85, SD=3.36). To understand this finding, the first author asked staff members why they thought participants listed so few people in their outer circles. The former Executive Director, Robert, shared an important insight related to participants’ marginal social and economic position:

As I think about my own tertiary relationships, those relationships tend to be facilitated by work, school, leisure... With most... participants not having access to work, school, leisure... I imagine they don’t have much of a venue for forming tertiary relationships.

Perceived Quality of Participants’ Social Relationships: Findings Based on the Facial Expression Chart

Participants were most likely to rate all types of network members as making them very happy. This was particularly true in terms of family members and staff with an average rating of 6.32 and 6.36, respectively. On average, participants indicated that other participants made them less happy than other network members, which is indicative of the complex and varied nature of participants’ relationships with each other and will be discussed below.

Participants who were higher functioning, measured by educational attainment, employment history, and ability to converse with others, more often rated their relationships with others as making them less than very happy. For example, one participant with a college degree rated other participants and individuals from the other day program he attended as a 5, indicating a more slightly negative feeling about his relationships with those other participants and individuals. Participants with less than a high school diploma, no previous employment history, and more challenges conversing with others, were more likely to label network members as making them very happy. This finding may reflect a coping response whereby marginalized individuals scale down their expectations (e.g., regarding social relationships) in response to having few choices or options available to them (Perkins et al., 2012); others have referred to this process as “immunization” (Goffman, 1961) and “miniaturization of satisfaction” (Rubenstein, Kilbride, & Nagy (1992). This is evidenced in responses of many participants to rate undependable and even estranged family as making them “very happy.” When probed for details, participants referred to instances where family members would visit once a month or every few months and bring snacks or a twelve pack of soft drinks with them. Their scaled down expectations resulted in them feeling loved and cared for by such a small gesture.

Insert Table 3.3 about here

Maximizing Choice in Social Relationships: Findings from Grounded Theory Analyses

Employing GTM, we developed a theoretical model (see Figure 3.1) that includes a central organizing process that we identified and have labeled “maximizing choice in social relationships”. Having choice in relationships was highly valued as participants

lack choice in many areas of their life due to the social and economic marginalization they face and their diagnosis of a chronic mental illness. In contrast with this general social exclusion, at the Oaks program participants have choices in all aspects of their engagement in the center. Among the most meaningful of choices is their choice with whom to form and maintain social relationships. As shown in Figure 1, social and environmental factors of the faith-based day program played a major role in participants' ability to maximize choice in their relationships with other participants and staff members. They maximize this choice by choosing to come to the center for "social" reasons, as evidenced by Theo's participation in bingo in order to build a relationship with a woman he was fond of. Other participants preferred to sit in the smoking section and not participate in program activities or engage in "fellowship" with others.

Insert Figure 3.1 about here

An interview with a staff member addressed the topic of choice. With regard to participants' choices at the Oaks, the Vicar said:

They can choose who they sit with at lunch, when they are waiting for the vans they can choose who they sit with, they can choose who they sit with at church...Who they hang out with in the smoking section.

Participants often did not describe this choice in relationships directly. However, the order in which they listed network members gave insight into this social phenomenon. When the first author asked Alex, a participant, to list the people with whom he was so close to he could not imagine his life without them, he immediately said about participants,

My friends...I got friends like...Craig, Dan, Brad...

Another participant, Leo, commented that he was not close to many people, but his responses indicated that he was close to Ron, also a housemate, with whom he chose to spend his time while at the Oaks. When I specifically asked about this friendship, Leo said:

Leo: Yeah, Ron is close to me.
 Interviewer: Would you put him in your network circle?
 Leo: Yeah, I'd put him in there [the middle circle].

Chronic Mental Illness and Social and Economic Marginality: Core Conditions that Shape Participants' Choices and Relationships

Core conditions related to participants' mental illness diagnosis include extreme social and economic marginalization within the wider community (see Figure 3.1). Forms of social marginalization include stigma and social exclusion related to symptoms of serious mental illness as well as having multiple comorbid physical illnesses and impairments. Economic marginalization results from poverty, low educational attainment, and a lack of access to material resources.

Related to social marginalization, multiple psychiatric hospitalizations disrupt relationships with others, including negatively impacting the few existing relationships some have with family members. During an informal interview, Dean explained this type of marginalization when asked how he was recovering from a recent inpatient stay at a local psychiatric facility:

My brother is irritated with me about [the hospitalization]. He doesn't want to talk to my psychiatrist or me.

In addition to limiting relationships with those from the wider community, the symptoms of mental illnesses can also negatively impact relationships within the program. In many instances, prolonged and sporadic absences do not result in strained

relationships at the Oaks, but in some situations they do. Some participants reported feeling insecure about the effects the symptoms of their mental illnesses have on their relationships with other program participants. Jean said:

Yes, that [symptoms of my mental illness] is a major problem. It is really hard for me to feel like I'm a friend or be able to keep a friend from the beginning up until the middle to the end. Basically, the whole thing about friendship is really difficult for me. My socialization and my anxiety ... can be very distorted at times where I'll worry about what [other program participants] are thinking or I'll be jumping the gun about what they may be thinking and they're not and sometimes that'll ruin relationships and then sometimes just because I won't speak up and talk to somebody, I won't even gain friendships.

Charlie echoed this sentiment and said that his "anger during episodes keeps me from being with other people (i.e., at the Center)." He indicated that he worried about how his symptoms would be interpreted or misinterpreted.

Many participants have comorbid physical ailments, which include diagnoses of diabetes, obesity, and high blood pressure. The Oaks recognizes these challenges and provides basic medical care at no additional cost to participants. Although these chronically mentally ill individuals require ongoing care for their mental illness, this does not necessarily result in them also receiving proper physical health care. While symptoms of mental illness sometimes separate participants, we observed how physical ailments can sometime serve as a point of connection inside the program. For example, Constantine and Walter originally knew of each other from the Oaks, but this bond was strengthened when they happened to be in the county hospital (a local safety net hospital where most receive care) at the same time for the treatment of diabetes. Now, when Constantine and Walter endearingly refer to each other as "Suga'," short for the colloquial term "sugar diabetes."

However, relationships forged through shared marginality are uncommon outside the center and problems related to social and economic marginality mostly contribute to difficulty in maintaining relationships and employment outside of the program. Robert, the former Executive Director, described the situation of many:

From talking to people and observing their home life, most of our people have very limited social circles. Beyond [attending] church [here], personal care homes, and any continued family connections they really don't keep in contact with other people. Most don't have access to a computer or a phone or anyway to travel to see people so they don't have anyway to keep in contact with old friends. Plus, if they grew up in any institution—jail, foster care, hospitals, etc. —then they wouldn't have maintained any friendships in those circles.

Most participants did not view employment as a viable option. Examples of this mentality were evident in interviews. Otis said that he was not “strong enough to work” and David said that his mental illness “[kept] him from working.” The one avenue participants had to earn income at the center was to make art for the art fair, but this only provided occasional pocket change.

The limited income that they receive – most participants receive Supplemental Security Income (SSI) that totals \$710 a month (Social Security Administration 2016) – combined with their mental and physical impairments substantially limits participants' ability to live independently. Despite these constraints, participants frequently spoke of their hopes of one day living independently, saying things such as “I'm going to get my own place” or “I'm goin' to move soon.”

Lack of income also reduces participants' independence by limiting access to transportation. Bill described his inability to use public transportation to travel outside of his neighborhood:

I used to ride Marta, but I would get on the train and ride all the way to the airport [south of the city] and get lost. I can only ride Marta when I have the money, when I sell a painting.

Related to most participants' limited income is their low educational attainment. As mentioned earlier, almost all of the respondents interviewed had less than a high school degree. The Oaks provided the monetary funds for several of these participants to try and obtain their GEDs in an attempt to decrease their economic marginality. Jean described some challenges related to her mental illness she had to overcome to obtain her GED while attending the center:

And so I'd back out [of getting my GED] or things would happen that would like put me in transition mode, worried or I'd have to move or something else would happen that would hinder me from going back. Last time I went [to GED classes] it took a lot of motivation and determination to get it, but I managed to get my GED.

Relational Strategies used to Maximize Choice in Relationships

Five relational strategies or subprocesses central to our core category were identified from the analysis and are presented in Figure 1. These strategies resulted in the development of five relationship types: (1) lookout or helping relationships; (2) friendships; (3) conflictual relationships; (4) romantic relationships; and (5) predatory relationships. These categories are overlapping and not mutually exclusive; most participants exhibit two or more of these relationships types concurrently. These connections also range in intensity. For example, friendships, which are described below, ranges along a continuum from close relationships that are in line with conventional conceptions of friendship to peripheral or weak ties.

Lookout or Helping Relationships

Facilitating program participation. Participants frequently express concern that someone might be left out of an activity, or, more commonly, without a ride. Often, participants will ask the van driver to wait on another participant who is late leaving a personal care home to board a van bound for The Oaks or go in search of a participant who they know needs a ride to a program activity, such as art or yoga practice. It is common to hear participants board the van and say, “She’s coming.” or “Wait, So and So ain’t on yet.”

Ensuring basic needs are met. Another common “look out” or “helping relationship” is ensuring that fellow participants’ basic needs and wants are met. For example, a few younger or more able-bodied participants routinely “look out” for elderly or physically disabled participants. Examples include helping others get on and off of the church van, providing assistance to those needing help moving to different locations on the campus, or helping people get food and carry it to a table.

Gifting. This relational strategy includes the giving of gifts, an act we refer to as “gifting.” Typical gifts are soft drinks, cigarettes, candy, or artwork, all valued commodities. Most personal care home residents are Social Security Disability recipients and most of their monthly incomes goes toward room and board. According to Georgia personal care home regulations, residents are required to receive a weekly personal needs allowance of \$5 and that stipend is all the pocket money some have (Georgia Department of Community Health, 2013). This adds considerable value to these commodities, as a pack of cigarettes currently costs about \$3.60. Gifts are not expected and are likely very much appreciated, but there is rarely any verbal acknowledgment of receiving a gift.

Friendships

When I asked participants what the word, “friendship,” meant to them, many of their responses reflected conventional meaning of the concept:

Someone you can trust.

Somebody you can divulge your secrets to. You can count on them. They won't turn you away if you show up on their doorstep.

Friends stick with you when something's wrong. You don't carry your burden to everyone—only your friend. You can take your problems to 'em and your business to 'em.

Others described “friends” in terms of more peripheral or weak ties:

A friend is someone who comes around once in a while.

I guess I can hold a conversation with [Susan and Kay], so I guess they are friends.

A few participants, most of whom had depressive symptoms as self-reported to the first author during observations and interviews, indicated that they did not have friendships.

One male participant who does not interact much with others at The Oaks described a friend as having divine qualities that perhaps he did not perceive in others at the Oaks:

“[A friend is] someone you can talk to like God. He gives comfort during stressful and disappointing times.”

Another female participant indicated that a friend needed to be someone who would contribute to her recovery and be a positive influence in her life. She described how she and another female participant she considered to be a close friend were working together to improve their life circumstances: “We've got our GED test going on, classes, and we both decided we would get our GEDs together.”

In some cases, roommates and housemates who attend the program together maintain closer friend relationships with one another than with other program participants. For example, two roommates at one personal care home, the Toney House*,

are inseparable and also “best friends.” They work together in the garden, eat together, and sit with one another during religious services. Several housemates from other personal care homes also routinely congregate together while at the program to talk or smoke.

The Program Director describes how relationships formed at The Oaks often become close and long lasting, and also how they frequently link other members of participants’ social networks together, widening their social circles and contributing to the sense of community that exists within the program:

[There are] long, long term friendships. We have people who have been coming to the program for fifteen years now. They have known each other [for a] very long [time] and their larger networks start connecting, like the program participants’ parents, their parents, become in a relationship with the church and the church with their family, so the networking starts getting broader and broader in a way that took me probably a year and a half to realize that one of our volunteer van driver’s mama knows program participant X’s step-dad, who lives over here and they do things, you know. It’s just like any other social network. There’s connection all over the place, platonic, romantic, sexual, non-sexual.”

Romantic relationships

While many participants at the program develop and maintain romantic relationships outside of the center, some of these relationships spill over into the center. Three long-term heterosexual relationships existed before data collection began at The Oaks and are still intact. One of these relationships developed at the center, while relationships among the other two couples developed within a personal care home setting. These relationships manifest differently during program hours. One couple maintains close physical contact from the time they arrive at the center until they leave in the early afternoon. They eat their meals near each other in the common room and they sit on the picnic benches and smoke together. They rarely interact with any of the other

participants, although they do not appear to be antisocial because they routinely join others in the smoking area, for example.

The other two couples arrive on the van together and may eat breakfast in the same group, but typically engage in different programming and interact with multiple other participants at the center. These other ties appear important to these couples, especially during times of emotional strife. Major areas of contention in these relationships include one partner's failure to adhere to medication or disruption in a relationship due to one partner's hospitalization (e.g., in a psychiatric ward).

In a few cases, the first author observed evidence of unrequited love. That is when one participant expresses a desire for romantic attachment and another participant, the object of this desire, expresses disinterest or repulsion. A participant named Robert described such a scenario, "You know Miss Caroline, well she was in love with me, but I didn't want anything to do with that. I was always trying to avoid her." In the case of both requited and unrequited love, flirting is common and includes compliments, such as "I like your hair" or questions like, "Do you have a boyfriend?" as well as physical advances, such as rubbing someone's back.

Conflictual relationships

Some participants have conflictual relationships with other participants. Although these conflicts often are subtle, some result in minor violence at the center, such as slapping, hitting, or pushing. These clashes rarely break up daily routine behavior because participants are accustomed to these disturbances and have learned to "work around each other," according to the Executive Director. Frequently, these altercations reoccur among the same participants; a certain group who have difficulty

getting along well with people outside of the program often find it hard to get along with others inside the program. Unfortunately, conflict can result in minor violence. One example I observed occurred while a participant was standing in the coffee line and misinterpreted something another participant said, which provoked him to push the perceived offender into the coffee cart. Another example I observed was when a participant intentionally stuck her cane across the aisle on the floor, which caused several people to trip. Similar to participants' tendency to sanction those who fail to help out when needed, this negative behavior was quickly sanctioned by another participant who yelled, "Hey! Stop it! I'm watching you."

Predatory relationships

Unfortunately, some participants maximized choice and used the freedom they had at the Oaks to prey upon some of the more vulnerable participants. A very small number of relationships are predatory, either sexually or financially, and are not tolerated by the Center. While these relationships occur with much less frequency than other types of relationships, they do exist and are important to acknowledge. Unfortunately, predators who themselves suffer from mental illness sometimes find their way into the program and, if perceived as posing a threat to others, are asked to leave. The Vicar explained the program's position with regard to sexual predation:

There are times when I have concluded, concerning certain people, that allowing them to be here puts the rest of the people at risk in the nature of sexual predation of some kind and I've had to tell people we cannot, it breaks our hearts to say this, but we can't deal with it. We don't have...someone to accompany you through the program day to make sure you don't do anything harmful to other people.

Consequences: Development of Meaningful Relationships

Due to their ability to employ various strategies to maximize choice in relationships at the center and develop various types of relationships, participants generally value their social relationships with other participants and find them meaningful (see Table 3.3). Although some relationships were more negative (e.g., conflictual or predatory), most relationships were positive and meaningful (i.e., supportive and involving mutual obligation). Findings show that many of these more positive relationships develop out of a commonality of experience (i.e., histories of chronic mental illness and associated social and economic marginality). These shared experiences enable participants to form bonds with others at the center that they have generally been unable to develop with members of the wider community. A staff member describes the nature of these bonds:

A lot of our folks have schizophrenia and with that comes all of the negative symptoms like flat affect and incoherent thought and that...is challenging to any relationship. When you can't communicate the way you want to communicate and you're not responding the way another person [finds] appropriate, it makes relationships more difficult. . . Here, we understand that. People who you are creating relationships with [one another here] are experiencing the same things.

Descriptive results from social network mapping show that on average, the size of participants' social support networks is small and participants generally include few program participants in their social network maps (Table 3.2). Qualitative data provide insight into this finding and show that program participants develop meaningful, long-lasting relationships not captured by the network map. Consistent with findings from social network mapping, qualitative data also show that many participants maximize choice in relationships by restricting the number of those they allow to become close.

Anna describes a strategy she employs to manage relationships and limit the emotional cost of forming too many close ties:

I don't really think I need that many friends. If I had that many friends, I wouldn't be able to live cause it's like one of those things where there's such thing as too many friends and then there's such thing as not enough or no friends. But I want to have- I want to have a balance. . . I'm not really wanting a lot of friends. It's too much to handle.

DISCUSSION

The chronically mentally ill maximize choice in relationships in the context of a faith-based day program despite the social and economic marginalization they encounter from the wider community. The repeated social interactions that this population engages in at the Center result in meaningful relationships.

During the early stages of deinstitutionalization, many researchers believed that the relationships that the mentally ill had with others were one-dimensional and not reciprocal. Research focused on mentally ill person's relationships with other family members, primarily because no other types of relationships were suspected. Estroff (1981) was the first to recognize that the mentally ill preferred to have relationships with each other. Two other studies indicate that the relationships that the chronically mentally ill have with each other are meaningful, i.e. they have supportive and negative aspects (Rosenfield & Wenzel, 1997, Yanos, et al., 2001). The present grounded theory study adds dimension to existing literature by providing insight on the context in which these meaningful relationships form. This vulnerable population has and continues to be socially and economically marginalized. These forms of marginalization result in the attendance at a faith-based day program. In this context, participants are afforded opportunities that they do not otherwise receive in their daily circumstances. One of

these opportunities is the ability to maximize choice in deciding with whom to develop relationships. They then employ a variety of relational strategies turning these repeated social interactions into meaningful relationships.

The findings of this study contribute to nuancing and extending social convoy theory. Originally, the social convoy model made claims about the aging general population. Recent research has extended this theoretical framework to study specific special populations, such as residents living in diverse assisted living facility settings (Kemp, Ball, & Perkins, 2013; Perkins et al., 2013) individuals aging with HIV (Perkins et al., 2015), older gay men (Tester & Wright, 2016), and individuals with late-life depression and dementia (Fiori, et al., 2006). The research presented here moves the convoy model in another new direction by focusing on low-income individuals aging with chronic mental illness, i.e. schizophrenia, bipolar disorder, and major depressive disorder. Findings show that central tenet of social convoy theory—that individuals carry a circle of individuals with them through life who provide protective physical and mental health benefits—apply to this population as well. As explored by social convoy theory, participants have had long-lasting relationships that they consider to have meaning. Relationships among the day program participants in this study are overlapping and multidimensional. Many of these friendships started at the inception of the program over 18 years ago. Although some participants' relationships are conflictual, many relationships among participants are positive and are an important source of social support. The center provides a social setting in which members form their convoy, allowing them to fill it, which they would not otherwise have given their marginalization and difficulties interacting with others because of their mental illness.

These relationships are particularly important given the many challenges that this vulnerable population experiences. The potential for isolation is extremely high based on the constant disruption due to hospitalizations and changes in living conditions. Some program participants drop out of the program for periods of time because they are hospitalized for mental health reasons or there are changes to their living situations. When they return from the hospital or they are able to obtain transportation from their new personal care home, they can easily slip back into existing social relationships that have been formed at the Center. This day program provides the ongoing structure that makes re-engaging with network members possible. This research indicates that breaks like these do not hinder relationship maintenance. Given this lack of family support that many participants experience, having access to these other types of continuous relationships is especially important.

Although the focus of this study was on participants' interactions with each other, a significant finding about their relationship to their families also emerged. Two recent studies indicated that the chronically mentally ill do not have significant relationships with their families. Smith (2013) observed that the peer-based social ties among the mentally ill replace kinship ties. The current study provides another perspective since, despite their often rare or even non-existent contact with family, participants at the Oaks perceived their relationships with family members as close and highly meaningful. This finding warrants further study.

Although this study provides insights regarding an understudied and vulnerable population, several limitations should be noted. This research project consists of a small, purposive sample of participants engaged in a day program in a major metropolitan area.

The interview sample was biased toward those who played a central role in the social life at the center and were able and willing to be interviewed and may not reflect the perspectives of those whom the first author was not able to interview. Observations and ongoing informal interviews with interview participants allowed for clarification of findings from interviews and for additional questions to be answered. This continued dialogue over time led to a fuller understanding of participants' perceived social relationships and informed data gathered during formal in-depth interviews.

CONCLUSION

Chronically mentally ill persons, by their own accounts, and by the observation of the researchers have meaningful relationships with each other. These findings counter previous research on the topic. This study developed a theoretical framework that sheds light on how the mentally ill maximize choice in the context of a faith-based day program. Within this context of choice, they are able to develop meaningful relationships despite the intervening effects of daily challenges, namely, social stigma, hospitalizations, and the effects of symptoms of mental illness. Findings grounded in theory have practical implications, including aiding in the reduction of stigma among the mentally ill and in the wider community by normalizing the often unconventional relationships the mentally ill have with each other, informing programmatic development at community supports, and directing future research across multiple fields.

REFERENCES

- Agtarap, S., Boals, A., Holtz, P., Roden-Foreman, K., Rainey, E.E., Ruggero, C. & Warren, A.M. (2017). The effect of depressive symptoms on social support one year following traumatic injury. *Journal of Affective Disorders*, 207, 398-405.
- Albright, D.L., Washington, K., Parker-Oliver, D., Lewis, A., Kruse, R.L., & Demiris, G. (2016). The social convoy for family caregivers over the course of hospice. *Journal of Pain and Symptom Management*, 51, 213-219.
- Akiyama, H., Antonucci, T.C., Takahashi, K., & Langfahl, E.S. (2003). Negative interactions in close relationships across the life span. *Journal of Gerontology: Psychological Sciences*, 58B, P70-P79.
- Ameiva, H., Stoykova, R., Matharan, F., Helmer, C., Antonucci, T., Dartigues, JF. (2010). What aspects of social network are protective for dementia? Not the quantity but the quality of social interactions is protective up to 15 years later. *Psychosomatic Medicine*, 72, 905-911.
- Andrews, F.M. & Withey, S.B. (1976). *Social indicators of well-being: Americans' perceptions of quality of life*. New York: Plenum Press.
- Antonucci, T.C. (1985). Personal characteristics, social networks and social behavior. *Handbook of Aging and the Social Sciences*, 94-128.
- Antonucci, T.C. (1986). Measuring social support networks: A hierarchical mapping technique. *Generations*, 10, 10-12.
- Antonucci, T.C. & Akiyama, H. (1995). Convoys of social relations: Family and friendships within a life span context. *Handbook of Aging and the Family*, 355-371.

- Antonucci, T.C., Akiyama, H., & Takahashi, K. (2004). Attachment and close relationships across the life span. *Attachment & Human Development, 6*, 353-70.
- Antonucci, T.C., Ajrouch, K.J., & Birditt, K.S. (2014). The convoy model: Explaining social relations from a multidisciplinary perspective. *The Gerontologist, 54*, 82–92.
- Antonucci, T.C., Fuhrer, R., & Dartigues, JF. (1997). Social relations and depressive symptomatology in a sample of community-dwelling French older adults. *Psychology and Aging, 12*, 189-95.
- Ball, M.M., Perkins, M.M., Whittington, F.J., Hollingsworth C., King, S.V, & Combs, B.L. (2005). *Communities of care: Assisted living for African American elders*. Baltimore, MA: The Johns Hopkins University Press.
- Birditt, K.S., Fingerman, K.L., & Almeida, D.M. (2005). Age differences in exposure and reactions to interpersonal tensions: A daily diary study. *Psychology and Aging, 20*, 330-340.
- Brooks, K. & Dunkel Schetter, C. (2011). Social negativity and health. *Social and Personality Psychology Compass, 5*, 904-918.
- Charmaz, K. (2014). *Constructing grounded theory, 2nd ed.* Thousand Oaks, CA: Sage Publishing.
- Creswell, J.W. (2012). *Qualitative inquiry and research design: Choosing among five approaches, 3rd ed.* Thousand Oaks, CA: Sage Publishing.
- Corbin, J.M. & Strauss, A.L. (2015). *Basics of qualitative research: Techniques and procedures for developing grounded theory, 4th ed.* Thousand Oaks, CA: Sage

Publishing.

Cruwys, T., Dingle, G.A., Haslam, C., Haslam, S.A., Jetten, J., & Morton, T.A. (2013).

Social group memberships protect against future depression, alleviate depression symptoms, and prevent depression relapse. *Social Science Medicine*, 98, 179-186.

Darbonne, A., Uchino, B.N., & Ong, A.D. (2013). What mediates links between age and

well-being? A test of social support and interpersonal conflict as potential interpersonal pathways. *Journal of Happiness Studies*, 14, 951-963.

Department of Health and Human Resources (2016). *Poverty Guidelines 2016*.

<https://aspe.hhs.gov/poverty-guidelines> (retrieved September 21, 2016).

Estroff, S. (1981). *Making it crazy: An ethnography of psychiatric clients in an American community*. Berkeley, CA: University of California Press.

Fiori, K.L., Antonucci, T.C., & Cortina, K.S. (2006). Social network typologies and mental health among older adults. *The Journals of Gerontology*, 61, 25-32.

Fiori, K.L., McIlvane, J.M., Brown, E.E., Antonucci, T.C. (2006). Social relations and depressive symptomology: Self-efficacy as a mediator. *Aging & Mental Health*, 3, 227-239.

Hollingsworth, L.D., Swick, D., & Choi, Y.J. (2013). The role of positive and negative social interactions in child custody outcomes: Voices of US women with serious mental illness. *Qualitative Social Work*, 12, 153-169.

Iglesias, S. & Arias, A.V. (2015). Structural and functional social support in elderly objective and subjective health ratings. *European Journal of Investigation in Health Psychology and Education*, 5, 243-252.

Garcia-Pena, C., Wagner, F.A, Sanchez-Garcia, S., Espinel-Bermudez, C., Juarez-

- Cedillo, T., Perez-Zepeda, M., et al. (2013). Late-life depressive symptoms: prediction models for change. *Journal of Affective Disorders, 150*, 886-894.
- Georgia Department of Community Health. 2013. Rules and Regulations for Personal Care Homes. Atlanta, GA: Georgia Secretary of State.
- Goffman, E. (1961). "Asylums: Essays on the social situation of mental patients. New York: Doubleday Anchor.
- Kemp, C.L., Ball, M.M., Perkins, M.M. (2013). Convoys of care: Theorizing intersections of formal and informal care. *Journal of Aging Studies, 27*, 15-29.
- Kuchibhatla, M.N., Fillenbaum, G.G., Hybels, C.F., & Blazer, D.G. (2012). Trajectory classes of depressive symptoms in a community sample of older adults. *Acta Psychiatrica, 125*, 492-501.
- Muller, J. (1995). Care of the dying by physicians in training: An example of participant observation research. *Research on Aging, 17*, 65-87.
- NVivo Qualitative Data Analysis Software; QSR International Pty Ltd. Version 11, 2015.
- Perkins, M. M., Halpin, S.N., Cooper, H, Justice, A.C., Johnson II, T. M., McInnes D., Rentsch, C. (2015). "Social determinants of health of veterans aging with HIV: A phenomenological study." *The Gerontologist, 55* (Suppl 2):41.
- Perkins, M.M., Ball, M.M., Kemp, C.L., & Hollingsworth, C. (2013). Social relations and resident health in assisted living: An application of the convoy model." *The Gerontologist, 53*, 495-507.
- Perkins, M.M., Ball, M.M., Whittington, F.J., & Combs, B.L. (2004). "Managing the care needs of low-income board-and-care home residents: A process of negotiating risks." *Qualitative Health Research, 14*, 478-495.

- Perkins, M. M. Ball, M.M., Whittington, F.J., & Hollingsworth, C. (2012). "Relational autonomy in assisted living: A focus on diverse care settings for older adults." *Journal of Aging Studies*, 26, 214-225.
- Rubenstein, R. L., Kilbride, J.C, & Nagy, S. (1992). Elders living alone: Frailty and the perceptions of choice." Hawthorne, NY: Aldine De Gruyer.
- Saha, S., Scott, J., Varghese, D., McGrath, J. (2012). Social support and delusional-like experiences: a nationwide population-based study. *Epidemiology and Psychiatric Sciences*, 21, 203-212.
- Santini, Z.I., (2016). Social relationships, loneliness, and mental health among older men and women in Ireland: A prospective community-based study. *Journal of Affective Disorders*, 204, 59-69.
- Sapin, M., Widmer, E.D., Iglesias, K. (2016). From support to overload: Patterns of positive and negative family relationships of adults with mental illness over time. *Social Networks*, 47, 59-72.
- State Bar of Georgia (2015). <https://www.gabar.org> (retrieved September 21, 2016).
- Strine, T.W., Chapman, D.P., Balluz, L., & Mokdad, A.H. (2008). Health-related quality of life and health behaviors by social and emotional support. *Social Psychiatry and Psychiatric Epidemiology*, 43, 151-159.
- Tester, G & Wright, E.R. (2016). "Older Gay Men and their Support Convoys." *Journal of Gerontology: Psychological Sciences*. DOI: [10.1093/geronb/gbw052](https://doi.org/10.1093/geronb/gbw052)
- Tsai, Y.F., Yeh, S.H., & Tsai, H.H. (2005). Prevalence and risk factors for depressive symptoms among community-dwelling elders in Taiwan. *International Journal of*

Geriatrics, 20, 1097-1102.

Wong, YL.I., Matejkowski, J., & Less, S. (2011). Social integration of people with serious mental illness: Network transaction and satisfaction. *Journal of Behavioral Health Services & Research*, 38, 51-67.

Yanos, P. T., Rosenfield, S., & Horwitz, A. V. (2001). Negative and supportive social interactions and quality of life among persons diagnosed with severe mental illness. *Community Mental Health Journal*, 37, 405-419.

Table 3.1 Interview Respondents' Characteristics (N=27)

Characteristic	Mean	Minimum-Maximum
Age (years)	49	27-66
	Frequency	%
Gender		
Male	22	82
Female	5	18
Race		
Black, African American	19	71
White	6	22
Other	2	7
Marital Status		
Never married	23	85
Married	1	4
Divorced	2	7
Widowed	1	4
Education		
Less than high school	12	44
High school	8	30
Some college	5	19
College degree	2	7
Self-rated physical health		
Excellent	5	19
Good	10	37
Fair	9	30
Poor	3	11
Self-rated mental health		
Excellent	3	11
Good	11	41
Fair	10	37
Poor	3	11

Table 3.2 Social Network Characteristics (N=27)

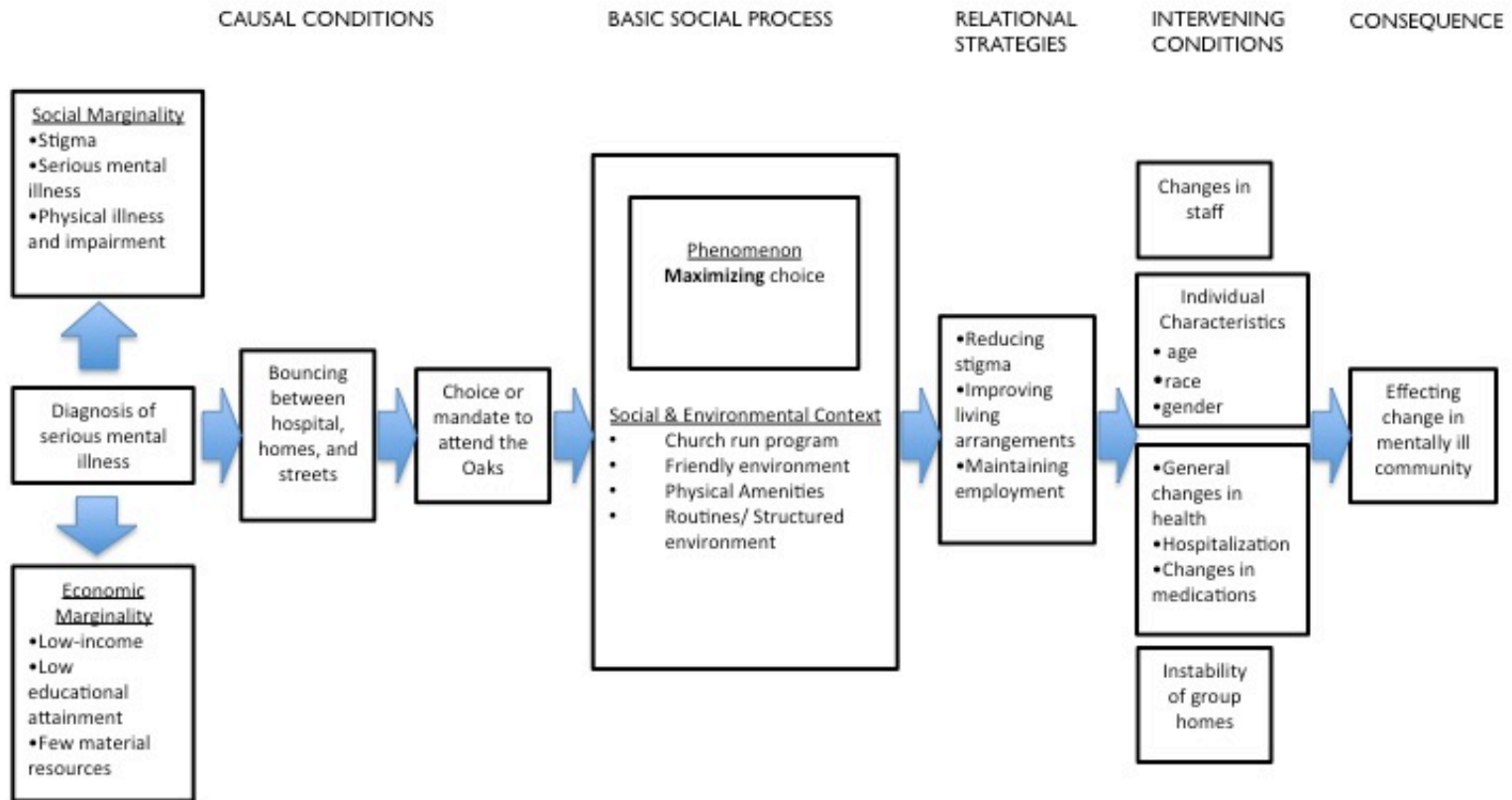
	Range	Mean	SD	% with at least one such tie
Size of Social Support Network	0-19	8.26	4.44	
Size of Inner Circle (number of close ties)	0-9	3.89	0.23	
Number of family members in inner circle	0-9	2.89	2.33	85
Number of participants in inner circle	0-4	0.41	0.89	26
Number of staff/volunteers in inner circle	0-1	0.08	0.27	7
Size of Middle Circle	0-10	2.22	2.46	
Number of family members in middle circle	0-2	0.3	0.67	18
Number of participants in middle circle	0-10	0.78	1.99	33
Number of staff/volunteers in middle circle	0-4	0.33	0.88	9
Size of Outer Circle	0-14	1.85	3.36	
Number of family members in outer circle	0-2	0.19	0.56	11
Number of participants in outer circle	0-10	0.93	2.24	29
Number of staff/volunteers in outer circle	0-1	0.15	0.36	15

Table 3.3 Perceived Quality of Participants Social Relationships (N=27)

Quality	7	6	5	4	3	2	1	Mean
Family	60	14	5	3	4	3	1	6.32
Participants	16	14	12	3	1	0	0	5.89
Staff	12	1	3	0	0	0	0	6.36
Other	19	10	5	3	3	1	4	5.65

Note. 7= very happy, 1= very sad/angry

FIGURE 1. THEORETICAL MODEL



CHAPTER 4

ENHANCED CAPABILITIES AND ENGAGEMENT IN THE RELIGIOUS COMMUNITY AT A FAITH-BASED DAY PROGRAM

ABSTRACT

Research on the relationship between mental health and religion often focuses on acute episodes experienced by the chronically mentally ill such as religious delusions. Additionally, much of the research indicates that the connection between religion and mental health is a negative one. However, another and less explored branch of research indicates that chronically mentally ill persons are more religious than the general population. Most of these studies are based on quantitative survey research. The current project aims to extend our understanding of why the chronically mentally ill may be more religious by taking a qualitative approach, to add to these quantitative findings. Using data from a study of the social relationships of the chronically mentally ill in a faith-based day program, we found that participants exhibit enhanced capabilities, i.e., reaching toward their maximum potential, as well as increased engagement in the religious community via corporate worship and collective participation in religious rituals.

KEYWORDS

Religion, capabilities approach, mentally ill, qualitative

INTRODUCTION

The relationship between religion and mental health has long been debated and researched in the literature (Keonig, King, & Carson, 2012). Most research involving those with chronic mental illness has focused on the role of religion in acute episodes. For example, studies have focused on how psychotic individuals perpetrate crimes against others stemming from religious delusions and influence (Kraya & Patrick, 1997; Field & Waldfogel, 1995; Silva, Leong, & Weinstock 1997; Waugh, 1986).

In contrast to these studies on religion in acute episodes, limited literature exists on the role of religion in the daily lives of the chronically mentally ill.

Consistent findings show that the chronically mentally ill are more likely to say they are religious (Neeleman & Lewis, 1994). These studies also typically examine either how the chronically mentally ill find comfort in their religiosity (Neeleman & Lewis, 1994, Pieper, 2004) or the role of religious belief and activities in recovery (Fallot 2007). The majority of these studies are survey-based (Kroll & Sheehan, 1989, Russinova, Wewiorski, & Dane, 2002) and lack a qualitative component to explain the meaning of increased religiosity among the chronically mentally ill. Due to this limitation, we aim to explain why such a phenomenon exists by examining the meaning of religious beliefs and practices among a marginal group of chronically mentally ill adults who attend a faith-based day program.

This qualitative study uses a deductive/inductive thematic analysis approach (Boyatzis, 1998; Fereday & Muir-Cochrane, 2006) to address two key gaps in knowledge: 1) the lack of studies of religion in the everyday lives of the chronically mentally ill; and 2) the lack of in-depth qualitative data in the few extant studies of religion and the chronically mentally ill. It incorporates the capabilities approach to determine if the religiously-oriented capabilities of *affiliation* and *senses, imagination, and thought* outlined by Nussbaum (2001) are present or even enhanced among this marginalized and vulnerable population of chronically mentally ill adults in a faith-based day program.

THEORETICAL BACKGROUND

“A religion is a unified system of beliefs and practices relative to sacred things, that is to say, things set apart and forbidden- beliefs and practices which unite into one single moral community called a Church, all those who adhere to them” (Durkheim, 1961)

[1912]:62).

Religiosity Among the Chronically Mentally Ill

As of 2016, among the general US population, almost 8 in 10 adults surveyed identified with a religion, mostly Christian, 53% considered their relationship with God as very important in their own life, 51% attended their religious community at least once a month, and 54% believed that religion can answer all or most of today's problems (Gallup, 2017). The relevance of religion to the chronically mentally ill in the United States is even greater. In a study of 52 psychiatric inpatients in Minnesota, 94% believed in God, 67% in the devil, 53% prayed or consulted the Bible, and 51% attended church weekly (Kroll & Sheehan, 1989). In a study of 406 psychiatric outpatients with chronic mental illness in Los Angeles, more than 80% indicated that they used religion to cope, and 65% reported that religion helped them to lessen symptom severity (Tepper, Rogers, Coleman & Malony, 2001). In an internet survey on alternative health practices used by individuals with chronic mental illness, the most frequently reported practices were religious activities (50%) and meditation (40%) (Rusinova, Wewiorski, & Dane, 2002). In a study of 121 Canadians, participants were asked to rate the subjective importance of religion in their lives on a Likert scale beginning with 0 (not important at all) up to 10 (essential). In regards to the importance of religion in daily life, the mean response was 6.5 (Borras et al., 2010). In sum, population-based studies indicate that religiosity is increased among the chronically mentally ill, but they do not include descriptive information as to why this is the case.

Most of the above empirical research is survey-based, but a small number of qualitative studies do exist. For example, Mohr and colleagues (2007) examined the religious characteristics of 115 outpatients with schizophrenia or schizoaffective disorder in Geneva, Switzerland. Findings showed that religion was central to the lives of 45% of patients, meaning that religion was important enough in these individuals' lives to influence experience and behavior. Additionally, the frequency of religious social activities and support from a religious community was inversely related to overall symptom severity.

Religion and the Capabilities Approach

The capabilities approach begins with a simple question: "What are people actually able to do and to be?" Nussbaum argues that the question is appropriate to ask in the context of equality because it is both simple and complex; it addresses the varied and complicated dimensions of human life. In short, the question encourages us to critically think about how to both identify opportunities for maximizing potential and to successfully attain the goal of equality, human dignity, and nondiscrimination for all individuals, whether it is women (Nussbaum, 2000), religious minorities (Nussbaum, 2000), or the cognitively impaired (Nussbaum, 2006, 2009). Nussbaum originally developed this approach in response to her time observing and interacting with women in less developed countries, particularly India, but since that time has expanded her paradigm to include other marginal populations, such as children and those with cognitive limitations (Nussbaum, 2006, 2009). We believe this work can be extended to even more vulnerable groups. While Nussbaum mentioned in an article (2009)

that there was a need to theorize about the equality and human dignity needed for the emotionally disturbed and mentally ill, to date she has not produced a work that addresses this disenfranchised group. This paper does not attempt to theorize about the central capabilities of the mentally ill in general; its purpose is to use the capabilities approach to better understand the role of religion among a group of chronically mentally ill persons attending a faith-based day program in Atlanta, Georgia. Findings in the study address an important knowledge gap and can inform future research.

While Nussbaum does not delineate a separate category for religious or spiritual capabilities, she does incorporate religious freedom and religious expression under two of her central capabilities. Nussbaum claims that “the liberty of religious belief, membership, and activity is among the central human capabilities” (Nussbaum 2000:179). Religious connection, freedom, and expression are present in two categories of the central capabilities, *affiliation* and *senses, imagination, and thought*. The central capability of *affiliation* involves two aspects. First is “being able to live with and toward others...to engage in various forms of social interaction” (Nussbaum 2011:34). Second is “being able to be treated as a dignified being whose worth is equal to that of others” (Nussbaum 2011:34). We argue equality, human dignity, and nondiscrimination in a religious context extends to the chronically mentally ill, a marginal and disenfranchised group, which Nussbaum has yet to address. We posit that religion potentially is a vehicle for the chronically mentally ill to obtain personal dignity as well a common connection with other believers.

The *senses, imagination and thought* central capability includes “being able to use the senses, to imagine, think, and reason- and to do these things in a ‘truly human’ [way]...being able to use imagination and thought in connection with experiencing and producing works in one’s own choice, religious, literary, musical, and so forth” (Nussbaum 2011:33). This central capability includes freedom of expression and freedom of religious exercise. The framework for religious expression and freedom is much narrower in scope than Nussbaum’s musings on the realms of education (e.g., Nussbaum, 2006, Nussbaum 2009) and politics (e.g., Nussbaum 2009), but this paper argues that is sufficient to apply to multiple marginalized groups, including the chronically mentally ill.

METHODS

Setting and Study Population

The Oaks is a church-sponsored community-based day program located in an urban neighborhood within the city of Atlanta. It serves a racially diverse group, primarily community-dwelling African-Americans and whites with serious chronic mental illness. The program has no formal membership process and anyone over the legal age of 18 is eligible to participate. The primary ways participants learn about the program are through social services agencies, group home providers, and word of mouth.

The day program provides a variety of services. Between 60 and 70 participants attend formal programs held every Tuesday and Thursday. Program attendees receive hot meals and have access to a community clothes closet. A primary recreational activity is art therapy and participants also can attend on-site

church services held on both program days. Basic physical health services also are provided and include foot care, assistance with general hygiene, weight monitoring, and blood pressure checks. Some program participants work for pay in the community garden on-site, which is supervised by a staff member, or help volunteer program staff in the kitchen. In addition to Tuesday and Thursday programs, many program participants also attend church services held at the church on Sunday mornings and participate in religious services or other activities held on other weeknights throughout the month.

All program participants have diagnoses of serious mental illness and are disproportionately older and African American. The majority of program participants have schizophrenia, which also includes paranoid schizophrenia. Other diagnoses include schizoaffective disorder and bipolar disorder. Currently, about 60% of the population is African-American and 40% is white. The majority of participants are female (about 60%) and more than one-third (40%) are aged 50 years or older. The oldest documented participant is 82 years old.

Data Collection

Primary data collection includes participant observation, informal interviews, and semi-structured interviews. All data were gathered at the main campus and at the art center during program hours between 9:00am and 1:00pm on Tuesdays and Thursdays. Additional observations were made on the van rides between the program participants' homes and the center. All interviews were conducted in the library on campus. Data collection began in August 2012 and ended in December 2015.

In-depth interviews. The first author conducted twenty-seven in-depth interviews with program participants and seven with program staff. Questions on participants' religious beliefs and practices were asked in part of a larger study focused on participants' social relationships. The semi-structured interview guide asked participants questions such as, "What meaning does religion have for you?" "How important is religion in your life?" and "Does religion play a role in the relationships you have with other participants at the Center?" In-depth interviews lasted between 30 minutes to an hour, 45 minutes on average, and were digitally recorded and transcribed verbatim.

Data Analysis

The method of analysis used in this study is "thematic analysis." Thematic analysis is a widely used analytic approach employed to identify and describe recurring patterns (or themes) within qualitative data that are central to one's research questions (Braun & Clarke, 2006). In this study, we adopt a hybrid thematic analysis approach (Boyatzis, 1998; Fereday & Muir-Cochrane, 2006) that incorporates both deductive (theory driven) and inductive (data-driven) analyses. First, we examined the data deductively to identify content that fit *a priori* codes based on Nussbaum's (2011) capabilities approach. Based on this template, we identified initial themes in the data. As analysis progressed, we also analyzed data inductively to identify other potential themes related to our general aim of understanding the meaning of religion in context of the everyday lives of our study participants and added additional candidate themes to our codebook. In addition to manual coding, analysis included running code and word queries using

NVIVO software 11. Via continued re-reading of the data, we investigated links between themes that we identified through deductive and inductive analyses and explored content that might extend, refute, or confirm existing theory. Through this process, we refined our codes and confirmed a new theme not specified in our initial coding template, resulting in the identification of three final overarching themes that we describe below.

RESULTS

In this qualitative paper, we identify three overarching themes in the data. Two of these themes confirm and map directly onto Nussbaum's two central capabilities of 1) *affiliation*, and 2) *senses, imagination, and thought*, which we conceptualize as *freedom of expression*. Nussbaum argues that *senses, imagination, and thought* or *freedom of expression* are required for equality, human dignity, and nondiscrimination in religious practice. We also identify an additional theme that together with the capabilities approach explains the meaning found in engagement in a religious community that we refer to as 3) *moral and ethical ways of living within a religious community*.

Affiliation

Religious beliefs and practices serve as a common bond among participants whereby they are able to "live with and towards others [and] engage in various forms of social interaction" (Nussbaum 2011:34). Via the coding process, we confirmed three types of *affiliation*: 1) connection through the discussion of religion and/or participation in religious rituals, 2) expressions of respect for others' belief system, and 3) equalizing staff/participant relationships

through corporate worship.

At the most basic level, participants of all ages recognize that their religious beliefs bond them to other like believers. These bonds are out of both expectation and preference. For example, Scott³, a 30-year-old African American man with schizophrenia, said that his mother always told him that “birds of a feather flock together,” indicating that as a Christian, he should interact and hang out with other Christians. This idea of interacting with fellow believers was echoed by Donald, a 40 year old African American man who also has a diagnosis of schizophrenia, who said, “I only hang out with Christians,” signifying a preference for spending time with like-minded individuals. Bernard, a 65-year-old white male, said, “We have [our religious beliefs] in common.”

Connection through the discussion of religion and/or participation in religious rituals

Some participants talked about how they had religiously-oriented conversations with other participants. Elise, a 28-year-old white woman with borderline personality disorder who lives independently, said that she had conversations with other participants about religion. These conversations were not limited to simply discussing religious topics, but expanded to the participation in religious rituals, which was an additional element of these common bonds.

I actually talk about [religion with other participants] sometimes.
Yes, I do. It's not about the talking that's powerful. It's more of the action that is taken through that.

By “action” Elise means the actual participation in religious rituals.

³ All names are pseudonyms.

Participants and staff talked about the bonding that occurred through participation in religious rituals and activities. Lilly, the health and wellness instructor, indicated that in some instances, believing in God is not sufficient comfort; participation in rituals is the “helpful” thing:

I’m sure there are people here who think there’s something wrong with them because [religious belief] is not helpful. I think that the actual services, though, there’s like a communion that happens between people and knowing what comes next and being a part of that...I think that is helpful.

Not only is participation helpful, but it is evident that collective participation holds a special meaning for participants. An example of this is singing during religious services. Arnold, a white male who holds outside employment as a part-time grocery store clerk, said:

Singing the songs, I can see some of the spirit of the others or some of their feelings. They’re not here to not sing and argue with other people to say, ‘Hey, you know, this is a good [experience]. Nobody says, ‘When I’m done singing I’m just going to forget about all of this.’

Chelsea, the vicar and acting Executive Director said that religious participation was a “common thing” that both bonded and occupied participants. She said:

It’s a common thing. It’s a commonality that they can talk about and share even if they don’t really talk about it and it gives them something to do. It’s an activity. It’s a shared activity. So it’s being close with somebody else. Proximity builds familiarity. And so it gives them something to do.

One way this “common thing” was achieved was through engagement in leadership roles (i.e., serving as an acolyte or reading liturgy). Two staff members, Chris, the art director, and Marian, the gardening director, respectively, observed this behavior among participants.

Everybody participates in the rituals of the church. You know the chalice bearers and the...acolytes. You know, doing those duties...they have to work together and learn together about what needs to be done and why it's being done. So that probably creates a different kind of bond because they are doing those kinds of things together.

And [worship] connects people to each other. And people are saying, 'Oh why don't you come be an [acolyte]' to each other. You know, 'I'm doing this, I can show you how.' I think it does foster [relationships].

Respect for others' religious beliefs

Not all participants who attend the Oaks and St. Francis are Christian believers; a small number of participants are Muslim. One Muslim woman comes because she enjoys the people she knows at the Center and actively engages in the art and gardening program. The two Muslim men come as a mandate from their personal care home managers, but find the Oaks welcoming nonetheless. Due to the type of strong affiliation that develops among participants, a level of respect develops between Muslims and Christians. Mainly this respect for freedom of religious belief is by the Muslim constituents of the program. Tiger, a 33 year old African American male who adopted the Muslim religion while incarcerated for a drug trafficking felony, indicated that he respected those with differing belief systems and recognized that "people really need their faith," whatever faith that may be:

I try to stay away so people could keep their faith and what they believe in. And I try my best not to...carry myself in a way where...there be disbelief in what [Christians at the Oaks] believe in...people really need their faith.

Maria, a 27-year-old African American woman who is also a Muslim, not only respects other participants' beliefs, but admires their religious ceremonies,

services that she also attends on a regular basis.

I love St. Francis and I love the way they practice their ceremonies and stuff and it's so pretty when they sing- especially when Amber [one of the NAMI connection leaders] sings.

Likewise, some of the Christians at the center recognize that some participants come from differing religions and respect the fact that not everyone at the center is Christian. Cindy, a 45 year old African-American who has experienced stigma related to both her mental illness and her HIV disease, values the sense of belonging she has found at the Oaks among both Christians and non-Christians:

[Other participants] got their own beliefs. I don't want nobody coming here scared to come here. I respect them like I respect me...

Another approach taken by Donald was to not bring up the topic of religion with other participants who he knew were not like-minded in their belief. He demonstrates his tolerance of other faiths in the following comment:

No, I don't bring up [religion] just in case they're Muslim or something like that and then we have to get into a conversation of if I have any friends that are different- of a different background.

Chris, a staff member, also spoke about a similar topic, referring to non-Episcopalians:

I would say most of the people, especially the ones that come to the day center program, come from a different religion, from a different [Christian] denomination so the practices would have been different. But being here, I don't think really makes that big of a difference. They know that they can come here and show their love of God and show their love of Jesus Christ and know that their faith in God and Christ have kept them safe.

The respect afforded by both the Muslims and Christians creates an environment of equality, human dignity, and nondiscrimination for all

participants.

Equalizing staff/participant relationships through corporate worship

An observation made by two staff members demonstrates that they believed that their participation in corporate worship with participants “equalizes” their relationships eliminating an “us and them” mentality. According to Lilly, the health and wellness director,

I’m always here on Wednesday nights and I always...get to see people. I mean I’m here [during program days] but I used to see people in that light and get to see me in that light. And [worshipping] is a different way of being with somebody and we’re both, during the Eucharist, and we’re both saying the things that you say, there is kind of a connection that doesn’t have anything to do with me being staff cause I’m not...a priestly kind of person.

Marian, echoed this, idea:

Yeah, I guess [religion facilitates relationships with staff members]...There’s still that sort of shared responsibility when we’re all together and everybody’s singing or everybody’s saying prayer or...you know, it equalizes.

This equalizing of social relationships was not just between participants, but was also present between participants and staff. When asked if religion connected him to various staff members, Donald, who had expressed a preference for “only hanging out with Christians,” indicated that he viewed many of the staff as family based on their shared religious beliefs and values, said:

Yes, they’re Christian and that’s an awesome thing. [We are] part of the same family...Jesus Christ’s family.

This statement indicates that religious participation does not delineate the staff and participants as “us and them,” but rather bonds participants together.

Freedom of Expression

The second central capability identified by Nussbaum as supporting the role of religious equality and human dignity is *senses, imagination and thought*, which highlights “producing works and events...religious, musical, and so forth.” There are two categories in this theme, including expressing creativity through art and music, and expressing emotion.

Expressing creativity through art and music

About half of the participants at the Oaks are involved in the art therapy program and common themes that appear in their art are religious in nature. Participants use mediums, such as clay, acrylic paint, and collage, to make religiously oriented artworks. These include images of Jesus, angels, and crosses. For example, Gloria, an African-American woman in her fifties with psychotic symptoms, often paints black cherub sculptures to sell at the art fairs. Bernard, a prolific artist who has his own room at the center to paint and store his artwork, said:

Well, I feel like I do my paintings for God...and that’s how I give.

Bernard uses his paintings not only as religious expression, but as a form of thanksgiving to God.

Expressing emotion

Some participants have difficulties with emotional expression, especially freedom of expression. Melvin said that in a way that he was jealous of the freedom of expression he witnessed among other participants because the symptoms of his mental illness often prevented him from feeling free or safe enough to exhibit these same behaviors.

However, many other participants referred to the opportunities the Center provided to positively express their emotions.

Another aspect of the *senses, imagination, and thought* is “freedom of religious exercise [and] being able to have pleasurable experiences” (Nussbaum 2011:33). This freedom of expression is evident in the participants’ descriptions of their engagement in the church services. As Peter said:

It’s just you can express yourself to the fullest extent to an altar.
You can just express all your emotions there, you know...

Participants also talk about how they can express emotions about their religious life in the various religious services that happen during the program day, such as morning or noonday prayer or during Bible study, which is led by a volunteer named Rupert, a white elderly male. Melvin, a 54-year-old male with bipolar disorder who usually keeps to himself, said:

I seen people shouting [from] the rooftops—how God did this for them, how God did that for them.

A popular event held for participants is "Saturday Night Live", a performance venue that offers participants the opportunity to express themselves both artistically and emotionally. The event is hosted on the second Saturday evening of the every month. Parishioners from another parish who have formed a contemporary band come to the Oaks and lead a corporate worship. The first half of the event is led by the band, which is composed of a singer, keyboardist, two guitarists, and a drummer. Participants can shout out numbers on the pages of the songbooks that they would like to sing. These include songs such as "Amazing Grace"

and "When the Saints Go Marching In". Participants really get into the vibe of the scene and stand up, even stand in the aisles to dance and sing along with the songs. Arnold said of the singing:

I can tell their feelings are singing in the songs. I can tell they like Jesus.

After a brief intermission, there is a talent show format, whereby participants can volunteer to sing or play the piano. There are an overwhelming number of volunteers; so many, that not everyone is able to participate. Typically participants stand up at the altar and sing gospel songs *a capella*.

Participants at the Oaks exhibit varying degrees of artistic and emotional expression. Although participants did not talk about why these variations existed, we interpret these findings as indication that for some, the amount and type of expression may be based on the symptoms of their mental illness.

Moral and Ethical Ways of Living Within a Religious Community

Another recurring theme identified through inductive coding -- *moral and ethical ways of living within a religious community* -- extends beyond the capabilities approach. Many participants responded that their religious beliefs served as a guiding force through the trials of their lives. Randy, a 44-year-old high school graduate with schizophrenia who resides with his parents and sister who also has a mental illness, said about religion, "It taught me how to be a right person." This idea of living "right" was also mentioned by Scott, who said:

If I believe in King Jesus and God the Father that they will take care of my wants and my needs but I just need to keep doing the right thing and keep going the right way, even though I slip and fall sometimes—I'm not perfect. But they're always here to help pick me up and help me out so I believe religion is a very

important thing in my life.

For several of the participants, these values are even more important because they have been in jail or have been homeless and have resorted to crime to get by. The notion of being a “right” person derives from a moral or ethical code instilled through participant’s involvement since they were children. As Peter said about his childhood:

When I was four years old [my father] became really involved in the church and they kind of forced religion on me. We was forced to go to church on Sunday mornings and evenings and Tuesday prayers...[my father was] making us go to Bible studies and other church activities...

Even though Peter was forced to go, the religious beliefs he has today were instilled in him as a child when he went to multiple church services a week.

For most participants this system is adherence to a Christian belief system, which serves as a foundation. Another variation of this “right” living is living righteously. Cindy spoke about righteousness: “If you [have] the righteousness of God, you ain’t got nothing to worry about.” These excerpts indicate that participants have moral and ethical codes by which they live and these unite them in a context such as a faith-based day program.

Many participants talked about their foundational religious beliefs indicating a sense of belonging to a community of like-minded people at the Oaks.

For example, Bernard said about his solid foundation in Christ:

I mean if I didn’t believe in Jesus, I wouldn’t believe in anything...[my belief] gives me a rock to stand on.

A participant, Patrick, an African American man with schizophrenia who works in the garden, said:

...Substantially, sustaining things, sustaining a foundation and priorities and keeping values all in the same balance so you won't fall here or fall there... You just gotta be careful where you step and how you step and religion kind of gives me a forefront on where I need to step.

Marian, the gardening director, also referred to this sense of belonging said that it mattered particularly for participants when the symptoms of their mental illnesses were negatively affecting their lives:

[Religion] is a kind of base...and having a sense of God's being there when things are really just horrible and nothing else is there and nobody else is there, you know, which probably makes [religion] more important than it is for me, who's had a rather privileged life and hadn't needed that kind of base so much.

In short, religion has a central position for many participants as they use it to bond to other participants and staff members. Donald said:

[Religion] is the main thing [in my life]...each normal processing group that you experience, a good relationship or relationships and find ones that are best for you—pick out ones that are best for you and [get to know] them and grow better. I think mine is the church...church is pretty much where it is, you know?

The church provides a community of like-minded individuals who express themselves through their religious beliefs.

DISCUSSION

The purpose of this qualitative study was to determine if the central capabilities outlined by Nussbaum (2000) regarding religious equality, including *affiliation* and *senses, imagination, and thought*, were relevant to a group of chronically mentally ill adults attending a faith-based day program and to explore the meaning of religious life among this group more generally. We aimed to identify themes that were particularly salient to this marginal and disenfranchised

group of adults. We found that those central capabilities theorized by Nussbaum were present among participants at the Oaks and that the additional themes of moral and ethical ways of living within a religious community and a sense of identity also were important themes.

We argue that some participants' common religious faith and practices are more central to their identity than other statuses. We determined this based on participants' willingness to discuss their religious beliefs and claim a religious affiliation. This made religious claims more often than they admitted to having a mental illness. There are several reasons that this likely the case. First, participants attend a faith-based day program, which is housed in a church and run by church clergy. Participants attend religious services on program days as well as Wednesday and Sunday nights, resulting in the centrality of religion in activities in their lives at the Oaks. Second, for some participants religious beliefs were likely instilled in them as children, providing them a template for "right living" despite living in dysfunctional family units. As their marginalization increased during adulthood, the Center gave them the opportunity to adhere to values that were familiar to them.

Another factor that could account for the importance of religion in these participants' lives is their early exposure to religion as a central aspect of their lives. Most of the participants at the center are African American. While the Black community is quite varied, many participants alluded to the fact that the Church was central to their social community, which is common among African-Americans in the South (Scheid & Brown 2010). Most participants talked about

how their religious beliefs were social in nature and that they not only felt connected due to similar beliefs, but they also enjoyed the fellowship and joint participation in religious rituals with other participants since they were part of a like-minded community. Even in cases where participants were Muslim, there was a respect for others who also shared a strong belief in the transcendent.

Beyond the question of why religion connects the participants in this day program, our data also revealed a number of details about how religion impacts their daily lives. In regards to Nussbaum's second central capability relating to religion, *senses, imagination, and thought*, participants were able to enjoy producing religious and artistic works, often a combination of both, providing them with a sense of equality (i.e., enjoying similar experiences as members in the wider community) and human dignity that is often absent in their daily existence. Several participants talked about how producing their own artwork or watching others create religious and artistic works resulted in enjoyment and fulfillment. Also, the pleasure derived from engaging in religious freedom and choice are welcome in a world where choice is extremely limited except for their time at the Center. The majority of participants, primarily those who live in personal care homes, are at the mercy of their personal care home managers to make every decision for them, including and not limited to decisions about medical treatment, how to spend their leisure time, what to eat, and when to go to bed. At the Center, and through religious and artistic freedom, participants make choices in activities ranging from what song to perform at Saturday Night Live to what artistic medium to produce artwork that is often religious in theme.

Participants employ moral and ethical ways of living, and techniques to maintain a sense of religious community to help them make sense of a disorienting world. Not only are participants marginal and disenfranchised socially and economically due to their chronic mental illness, but they also suffer from disorienting symptoms of mental illness, which at times can be confusing as they skew perceptions of time and social relationships. By having a moral and ethical code and a strong sense of community rooted in religious beliefs that help them “live right,” they are able to find stable values that do not alter even though their reality sometimes does. Many hold these values dear because, much like the central position of the church in their social community breeding familiarity, the values and ethical guidelines that they live by were adopted in adolescence and also are familiar to them.

While we have extended the capabilities approach, some study limitations do exist. First, our study sample was a small purposive sample of a group of chronically mentally ill persons attending a faith-based day program and findings cannot be applied to the general mentally ill population.

CONCLUSION

Scant literature exists on religiosity among the chronically mentally ill. The literature that does exist indicates that the chronically mentally ill are more religious than the general population. This project adds to the literature by incorporating a qualitative dimension to many survey-based studies and identifies relevant themes that explore the religiosity of chronically mentally ill adults who attend a faith-based day program. In short, mentally ill people share similar

characteristics with the general population. Religion serves as an avenue for the development of social relationships, provides opportunities for freedom of religious and artistic expression, and serves as a moral and ethical system for “right” living.

REFERENCES

- Borras, L., Mohr, S., Gillieron, C. et al. (2010). Religion and spirituality: How clinicians in Quebec and Geneva cope with the issue when faced with patients suffering from chronic psychosis. *Community Mental Health Journal, 46*(1), 77-86
- Fallot, R.D. (2007). Spirituality and religion in recovery: Some current issues. *Psychiatric Rehabilitation Journal, 30*, 261-270.
- Field, H.L., & Waldfogel, S. (1995). Severe ocular self-injury. *General Hospital Psychiatry, 17*, 224-227.
- Gallup (2017). *Religion*. Retrieved from <http://www.gallup.com/poll/1690/Religion.aspx#2>
- Kirov, G., Kemp, R., Kirov, K., & David, A.S. (1998). Religious faith after psychotic illness. *Psychopathology, 31*, 234-245.
- Koenig, H.G. (2012). Religion, spirituality, and health: The research and clinical implications. *International Scholarly Research Network*.
- Koenig, H.G., King, D.E., & V.B. Carson. (2012) *Handbook of religion and health, 2nd ed.* New York: Oxford University Press.
- Kroll, J. & Sheehan, W. (1989). Religious beliefs and practices among 52

psychiatric inpatients in Minnesota. *American Journal of Psychiatry*, 146, 67-72.

Kraya, N.A., & Patrick, C. (1997). Folie a deux in forensic setting. *Australian and New Zealand Journal of Psychiatry*, 31, 883-888.

Mohr, S. (2013). Religion, spirituality, and severe mental disorder: From research to clinical practice. *APA Handbook of Psychology, Religion, and Spirituality, Vol: 2. An Applied Psychology of Religion and Spirituality*, ed. by K.I. Pargament, pp. 257-273

Mohr, S., Gillieron, C., Borrás, L., Brandt, P.Y., & Huguelet, P. (2007). The assessment of spirituality and religiousness in schizophrenia. *Journal of Nervous and Mental Disease*, 195, 247-253.

Neeleman, J., & Lewis G. (1994). Religious identity and comfort beliefs in three groups of psychiatric patients and a group of medical controls. *International Journal of Social Psychiatry*, 40, 124-134.

Nussbaum, M.C. (2000). *Women and human development: a capabilities approach*. New York: Cambridge University Press.

Nussbaum, M.C. (2006). *Frontiers of justice: Disability, nationality, and species membership*. Cambridge, MA: Harvard University Press.

Nussbaum, M.C. (2009). The capabilities of people with cognitive disabilities. *Metaphilosophy*, 40 (3-4).

Nussbaum, M.C. (2011). *Creating capabilities: the human development approach*. Cambridge, MA: Belknap Press of Harvard University Press.

Russinova, Z., Wewiorski, N.J., & Dane, C. (2002). Use of alternative health care

practices by persons with serious mental illness: Perceived benefits.

American Journal of Public Health, 92, 1600-1603.

Silva, J.A., Leong, G.B., & Weinstock, R. (1997). Violent behaviors associated

with the antichrist delusion. *Journal of Forensic Sciences, 42, 1058-1061.*

Tepper, L. Rogers, S.A., Coleman, E.M., & Malony, H.N. (2001). The prevalence

of religious coping among persons with persistent mental illness.

Psychiatric Services, 52, 660-665.

Waugh, A.C. (1986). Autocastration and biblical delusions in schizophrenia.

British Journal of Psychiatry, 149, 656-658.

CHAPTER 5 DISCUSSION

The goal of this qualitative project was to explore the world of a group of chronically mentally ill persons who attend a faith-based day program. We additionally, aimed to develop theory and extend conceptual frameworks including the capabilities approach (Nussbaum, 2011), the social convoy model (Kahn & Antonucci, 1980), and the concept of mediating structures (Berger, 1976). The goal is achieved through the development of three interrelated studies presented in this dissertation. Main topics include the dyadic social relationships among participants, the role of the organization as a mediating structure leading to enhanced capabilities, and integration of the capabilities approach and social solidarity in regards to religious rituals practiced at the Oaks⁴. Three common threads woven through these papers are enhanced capabilities, maximizing choice, and engagement in the community at the Center.

While each paper's focus is on a different theme, all three categories are present to some extent. In addition to these themes there are other similarities. First, all three papers explore the same study population in the same setting, i.e. a group of chronically mentally ill persons who attend a faith-based day program in the Atlanta metropolitan area. Second, the theoretical and conceptual models have the same basic beginning; participants of the program are socially and economically disadvantaged due to their diagnosis of a chronic mental illness.

⁴ All names are pseudonyms

The following sections provide a detailed discussion of each of these themes by presenting original insight rooted in theoretical and conceptual frameworks, which are supported by examples identified in the data. Policy implications and future directions follow. A conclusion, then, summarizes main points of the dissertation in its entirety.

The Capabilities Approach

The central overarching conceptual framework that guides the entirety of this project is the capabilities approach developed by Nussbaum (for review see Nussbaum 2011). The central question of this approach is: “What are people actually able to do and to be?” The aim of this approach is to promote equality, human dignity, and nondiscrimination for vulnerable and marginal populations, including but not limited to racial minorities, gender minorities, those with cognitive limitations, and the chronically mentally ill. In the case of chronically mentally ill persons who attend a faith-based day program, this manifests itself in participants reaching toward their maximum potential. We refer to this as developing enhanced capabilities.

The capabilities approach, also known as the human development approach, was derived from Nussbaum's work on the disadvantageous circumstances of women in developing nations who have fought, mainly through the court system, for equality in the realms of family, finance, education, politics, and reproductive rights, to name a few. I argue that it is also relevant for interpreting the situation of a marginal and disenfranchised group of chronically mentally ill adults attending a faith-based day program. Mentally ill persons

constitute a minority group who are marginalized due to the severity and persistency of their mental illness. Additionally, many participants are also racial minorities so they experience increased stigma and marginality. They are socially marginalized due to stigma, the symptoms of their mental illness, and their often co-morbid physical illnesses and impairments. They are economically marginalized in that they are low-income, have low educational attainment, and possess few material resources.

In most instances, minorities are marginalized in some way. We have outlined above the ways in which chronically mentally ill persons are marginalized both socially and economically. Keeping this in mind, we selected a framework for what we witnessed at the Oaks—equality, human dignity, and nondiscrimination. Via the literature and observations with other populations, we aimed to identify what was observed and heard during interviews—participants reaching a threshold of maximum potential. How was it that the participants at the Oaks were so extremely marginalized and yet thrived in their community? The common denominator was their participation at the Oaks, which provided a setting within which they could enhance their capabilities.

There are ten central capabilities outlined in Nussbaum's (2011) work including,

1) *life*; 2) *bodily health*; 3) *bodily integrity*; 4) *senses, imagination, and thought*; 5) *emotions*; 6) *practical reason*; 7) *affiliation*; 8) *other species*; 9) *play*; and 10) *control over one's environment*. These capabilities range from internal states, apparent in the capability *senses, imagination, and thought*, or “being able to use

the senses, to imagine, think and reason- and to do these things in a ‘truly human’ way” (Nussbaum 2011:33), to external states, apparent in the capability *affiliation*, or “being able to live with and towards others” (34). One capability, *other species*, even highlights an individual’s right “to live with concern for an in relation to animals, plants, and the world of nature” (34).

In the paper addressing the role of mediating structures in enhancing participants’ capabilities, we identified four relevant central capabilities (*emotions, affiliation, play, and control over one’s environment*) that mapped onto our findings. Through this deductive approach, we found that the Oaks provided opportunities for participants to reach toward their maximum potential vis-à-vis these four capabilities. As seen in our conceptual model (see Figure 1 in the mediating structures and enhanced capabilities paper), the empowerment participants acquired through feeling as though they were part of a “larger thing” resulted in enhanced capabilities. These capabilities indicate that participants reach toward their maximum potential in a variety of capacities, primarily social ones. This opportunity to engage in social activities decreases participants’ marginal status and increases meaning in their lives.

Utilizing a similar deductive approach in the paper on enhanced capabilities within the context of engaging in a sense of the collectivity, we highlighted two central capabilities applicable to this relationship (*affiliation and senses, imagination, and thought*). Nussbaum (2000) identified these two capabilities as being particularly salient to the practice of religion, the underlying topic of that paper. While Nussbaum does not delineate capabilities specifically

for social institutions of religion, the value of her central capabilities is that at least some of the central capabilities are applicable to any social institution. In regards to this paper, we position the practice of religion as capabilities (an external state and internal one) that lead to engaging in a sense of the collectivity. This engagement in a sense of the collectively is examined in detail in a later section of this discussion.

While our grounded theory study did not explicitly discuss enhanced capabilities, it can be argued that they are present in the consequences of relational strategies. That is, these enhanced capabilities are visible through the opportunities and abilities to develop meaningful relationships with other participants at the Oaks. Participants reach toward their maximum potential through the development of those relationships.

Nussbaum (2006; 2009) indirectly addressed those with cognitive limitations in earlier works, wherein she called for educational equality for children (see Nussbaum 2006) and later for educational and political equality for all individuals with cognitive limitations (see Nussbaum 2009). In her 2009 article, she made the distinction that those with cognitive impairments (e.g., those on the autism spectrum) differed from those with “emotional disturbances and mental illness.” She suggested that she would theorize about the rights owed to the latter group in the future, but to date has yet to produce any work on this particular marginal group. While I do not claim to theorize on the capabilities of the chronically mentally ill as Nussbaum does with other marginal groups, I do offer extensions of the approach to apply to a certain group of mentally ill adults

who attend a day program within a specific context. Her approach has been very helpful in illuminating the core strengths of the program, and the commitment of the program participants, staff, and larger community to supporting it over its 20 years of existence.

Staff was a driving factor in creating an environment of equality. Beginning when participants arrived in the morning, staff casually welcomed participants in a friendly way, acknowledging them and inviting them to come to the fellowship hall for a cup of coffee. Throughout the day, staff engaged participants and had “real” conversations with them. They developed friendships by simply participating in the same activities. For example, the art director would give advice to a participant as to how to improve her artwork and make it more sellable. This common bond developed into real relationships. The same art director spoke of her 50th birthday party and the presence of one participant who ended up spending the night because she had stayed so late to clean up after the guests left. The informal nature of these interactions and the disclosure by multiple staff members about their own mental health diagnosis naturally led to an environment of equality, a place free from stigma. Link and Phelan (2001), in their conceptualization of stigma, list the separating of “us” and “them” as an aspect of stigma. Staff at the Oaks does not foster a community of “us” and “them.” This was of key importance to the Oaks.

Maximizing Choice

In our grounded theory study, we identified maximizing choice as the basic social process whereby participants employ relational strategies (e.g.,

friendships, lookout/helping relationships, etc.) that result in the development of meaningful relationships. This was evident in interviews with staff. We discovered that participants lacked choice in almost every aspect of their lives, except while at the Oaks. For example, a participant talked about having to go to bed by 8 pm, a mandate by the caretakers in the personal care home in which he lived. Another example was a participant's description about the requirement to attend a Bible study led by their personal care home manager on Wednesday evenings. We argue that these descriptive examples are evidence of lack of choice in all facets of life. However, we noticed that participants thrived (e.g., developed meaningful relationships and some engaged in in-house employment) at the Oaks precisely because they had the freedom to choose. These choices ranged from deciding whom to sit next to in the fellowship hall for meals, whether to attend programming or sit in the smoking section, or what art medium to create artwork in on a Tuesday morning. While these cases appear simplistic, they are real and accurate examples of the types of choices participants have the option of independently making.

This idea of maximizing choice is present in the identified themes in the papers on enhanced capabilities as well. In the paper on mediating structures and enhanced capabilities, participants maximized choice through the empowerment they gained from their participation at the Oaks. They made decisions regarding how to reduce stigma, how to maintain employment inside and outside of the Oaks, and in some cases, improve their living conditions

One way that participants reduced stigma was through their involvement in the National Alliance on Mental Illness (NAMI). NAMI is a national organization that advocates, educates, and leads events to “fight stigma and encourage understanding” (NAMI 2017). The Oaks hosts a NAMI connection group every Thursday afternoon and the members often walked together in the citywide NAMI walk. Throughout the observation period, there were several instances when connection group leaders recruited participants at the Oaks to come to the annual walk whether they regularly attended the connection group or not. Once a year, participants would travel to St. Simons Island, in South Georgia, for the annual statewide NAMI conference. While there, participants attended presentations and discussion panels focused on mental health topics. In one observation, the first author noted that some participants at the Oaks talked to other participants about their presentations on their lived experiences with mental illness. The presence and support of a NAMI connection group at the Oaks is the main avenue by which participants actively reduce stigma in the community.

An example of improving living conditions is illustrated by a participant who talked to a staff member about changing his personal care home to one that granted him more freedom and independence during the day. He chose to talk to the staff member about his circumstances, he chose to call the new personal care home manager to talk about moving in, and after receiving satisfactory answers about the details of the living conditions at the house, he chose to pack up his meager belongings at the old personal care home and move to a new one. Later, he described a typical day to the first author, which included roaming the new

neighborhood before stopping in Starbucks for a cup of water. He relished his opportunity to choose how to spend his day, a choice not previously available to him.

Choices are not always as dramatic as they are in the previous example. In the paper on religion and enhanced capabilities, participants engaged in making choices in regards to religious and artistic expression. Participants were either asked by staff or volunteered for leadership positions during services to serve as an acolyte, read the liturgy, or collect the offering. At Saturday Night Live, the monthly musical event hosted by another parish, participants volunteered to perform during the talent show portion and selected songs to sing or play to the audience. Participants had multiple opportunities to choose which art projects they would like to do on program days. They could choose among sculpture, stained glass, woodworking, painting, collage, or drawing. In all of these examples, participants never seemed overwhelmed with these many options; instead they appeared delighted and pleased to have the opportunities to make these decisions for themselves.

The enjoyment of choice was evident in their actions as most participants took advantage of these opportunities. For example, during Saturday Night Live, the number of volunteers to participate in the talent show portion exceeded the allotted available slots, making a first-come first-served policy necessary; some participants had to be turned down. Participants always lined up early for the art van to pick them up and take them to the art center down the street. Sometimes, so many people wanted to go that the van had to make two trips to accommodate

everyone. Between scheduled programming, the smoking section would become so crowded that people had squeeze in to make room for everyone on the picnic benches and often several people were still left standing. When given the opportunity, participants chose to participate in social activities.

We concluded that participants scaled down their expectations (e.g., regarding social relationships) in response to having few choices or options available to them outside of the Oaks (Perkins et al., 2012); others have referred to this process as “immunization” (Goffman, 1961) and “miniaturization of satisfaction” (Rubenstein, Kilbride, & Nagy (1992). In short, individuals decrease their expectations in relation to their diminishing range of choices. This is especially evident for older populations and we argue it is also relevant for this marginal and disenfranchised group of chronically mentally ill adults. This miniaturization of satisfaction was most evident in interviews with participants when they rated their satisfaction with others using the facial expression chart created by Andrews and Withey (1976). Those who were lower functioning rated their social relationships more favorably than those who were higher functioning. The scaling down of expectations in social relationships was an act of protection of their emotions, a lack of experience with emotionally supportive others, and a response to notions of differences in normality and abnormality.

Scaling down expectations in choice was visible in participants’ actions at the Oaks. The first author rarely observed a participant demand anything like more paint to paint with, or more food to eat. With the exception of one participant, everyone even obeyed the three cup limit on served coffee in the

morning. A clear example of choice within scaled down expectations was evident in the Bingo games and prizes. The attractive quality of Bingo was that participants could choose an item from a Rubbermaid bin when they won a game. (The game was not complete until everyone had won a game of Bingo and selected a prize). The prizes included small gifts such as travel size toothpastes or an allotment of 10 Skittles, and available prizes varied depending on the week. Some participants were selective and carefully decided which prize to take, indicating that they enjoyed the opportunity they had to choose; taking time is an indication of a valued experience. In some cases, participants had a difficult time choosing prizes because they were not accustomed to having opportunities to make a range of choices. The leader of the Bingo limited the time to choose, which may appear strict by some standards, but was also helpful for people who did not have a lot of opportunities to make choices and carefully considered their many options.

As a result of maximizing choice in a variety of arenas at the Center, most participants chose to develop meaningful relationships with other participants, some chose to join the NAMI connection group, and some played Bingo in a group setting. These are all examples of participants engaging in the collectivity, whereby they thrived within the social solidarity that the Oaks provided.

Engaging in the Collective

Another major concept identified in the data was engaging in the community. In the conceptual model developed in the paper on mediating structures and enhanced capabilities article (see Figure 2.1), the engagement in

the social community resulted from a sense of belonging to a “larger thing” or an attachment to the social institution. Two things, a tangible place, the social institution that is the Oaks, and the intangible feeling of social connection to others comprised the “larger thing”. This social structure underlies the social collectivity that is present at the Center.

The Oaks is a permanent social institution; its inception was in 1996. While many participants have attended the Oaks during that time (ranging from attending for a period of time or intermittently over many years), a couple of participants have attended the program since it began in the mid-1990s. In one case, a participant who attended the program from the outset transitioned from being a participant to working at the Oaks as the janitor. He now works 15 to 20 hours a week.

Since the Oaks is a faith-based organization, naturally, there is a religious component to the program. The type of relationship between the religious organization and the social collective present at the Center is best summarized by the theorist Sonya Hauser (2013):

We cannot be social without being religious, insofar as we draw our sense of ourselves from common meaning, and we cannot be religious without being social, even if some of the most intense religious practices may be undertaken in isolation. Beliefs and practices alike are drawn from the collective pool (6).

This quote encapsulates the atmosphere at the Oaks; religion and social participation are tightly intertwined.

In the enhanced capabilities paper focusing on the close relationship between religion and the social, we found that engagement in the community

resulted in a theme we refer to as moral and ethical living in a religious community. Many participants adhered to a code of morals and ethics from their childhood experiences in the church, and these beliefs were strengthened through their participation in collective religious rituals, such as singing during services or at Saturday Night Live. In what is arguably a modest form of collective effervescence (Durkheim 1961 [1912]), participants and staff bonded through their shared religious beliefs that were manifested through their religious practices.

In the social relationships paper we saw that participants engaged in the social community at the Oaks via maximizing choice when they initiated, fostered, and maintained meaningful relationships with other participants. By maximizing choice they drew on an identity as not only a participant at the Oaks, but also as a friend. In short, they were part of the community, whereas in their experiences outside the Oaks, they were marginal and disenfranchised.

PRACTICAL IMPLICATIONS

Findings in all three papers contain multiple practical implications in addition to theoretical and conceptual ones described above. First, findings can aid in the reduction of stigma among the mentally ill and in the wider community. For example, bringing awareness to participants that they do possess social relationships with each other, as defined in their own words, helps them normalize these unconventional relationships in their minds. This increases their confidence to develop social relationships with others in the wider community, including those with family members, neighbors, potential friends, and potential co-

workers. This can decrease both self-stigmatization and stigmatization held by the wider community. Findings can also aid in reducing stigma through the empowerment of these chronically mentally ill adults to maintain employment, both inside and outside the Oaks. One of the interviewed participants actively held outside employment during the observation period and multiple others had held employment at some point in their lives. Arguably, the experience and practice that some of the gardeners gained through their work could result in outside employment as well, which would aid in stigma reduction as they would be able to demonstrate strong work ethics, skills acquired during their employment at the Oaks.

Secondly, findings can inform programmatic development at other community supports. The state of Georgia is experiencing difficulties managing the recent problems of dealing with deinstitutionalized adults in the community. In some cases, state employees have even housed the mentally ill in unlicensed personal care homes and extended stay motels. Clearly, this is troublesome, as these individuals are receiving neither adequate nor appropriate treatment. The Oaks serves as a model for successful living through the provision of opportunities of choice, resulting in enhanced capabilities. In short, the majority of participants at the Oaks are not only surviving at the Oaks, but they are thriving in this environment.

Thirdly, findings can direct future research across multiple fields. Health research has traditionally been and continues to be interdisciplinary in nature. Successfully funded grants frequently consist of a wide range of researchers

including, social scientists, epidemiologists, medical doctors, nurses, public health practitioners, and health economists, indicating that funding sources encourage and support cross-discipline collaboration. Research by scholars representing a variety of health fields, on a small, purposive sample such as the Oaks, could provide additional insights in multiple disciplines.

FUTURE DIRECTIONS

Future directions of research include both additional research on the population at the Oaks as well as transferring knowledge gained from this group of chronically mentally ill individuals to other settings. In regards to further research on the participants at the Oaks, there are multiple opportunities for continued engagement. For example, the art and gardening programs are the hallmarks of this community support. Identifying characteristics of the various participants who successfully engage in each of these programs could help the Oaks determine what aspect of these programs lead to sustained participation and enhanced capabilities for all participants.

In regards to transferring the knowledge acquired from the Oaks, it should be determined if the same processes occur in other settings. Determining if the processes of maximizing choice and empowerment that result in enhanced capabilities are present among the chronically mentally ill in different contexts (e.g., secular programs, different socio-demographic compositions of study populations, and programs located in various geographic locations) can widen the application and further refine the capabilities approach.

Lastly, in line with the notion of extending theory, we applied the social convoy model to a new population, the chronically mentally ill. Future research would benefit from exploring various other mentally ill populations. For example, some of the participants at the Oaks are over 50 years old, an age considered “old age” for this population. New insights were derived from exploring the lives of these older adults. Locating a population comprised of older chronically mentally ill persons and framing the research approach through the utilization of the social convoy model would expand the scope of this conceptual framework.

CONCLUSION

In contemporary society, the chronically mentally ill are socially and economically marginalized due to their mental illness diagnosis. While marginal and disenfranchised in these ways, the group of chronically mentally ill persons we studied thrives within the context of the Oaks precisely because they are treated with equality, human dignity, and nondiscrimination by both staff and each other. Through a qualitative approach, we found that participants at the Oaks cultivate enhanced capabilities, maximize choice in relationships and other opportunities afforded to them, and conform to a sense of the collectivity. We found that most participants maximized their full potential in this setting, albeit in nuanced ways for many. We developed theory and contributed to conceptual frameworks based on these findings and recommended practical and policy changes. While there is abundant literature that focused on the negative plight of the chronically mentally ill in the current mental health care system, we

discovered and studied a community support where the mentally ill are flourishing.

REFERENCES

- Berger, P. L. (1976). In praise of particularity: The concept of mediating structures. *The Review of Politics*, 38, 399-410.
- Durkheim, Emile. (1961). *The elementary forms of the religious life*. New York: Collier Books
- Hauser, Sondra L. (2013). *Durkheim in disciplinary dialogue: A centenary celebration of the elementary forms of religious life*. New York: Berghahn Books.
- Link, B.G., & Phelan, J.C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363-385.
- Nussbaum, M.C. (2000). *Women and human development: a capabilities approach*. New York: Cambridge University Press.
- Nussbaum, M.C. (2006). *Frontiers of justice: Disability, nationality, and species membership*. Cambridge, MA: Harvard University Press.
- Nussbaum, M.C. (2009). The capabilities of people with cognitive disabilities. *Metaphilosophy*, 40 (3-4).
- Nussbaum, M.C. (2011). *Creating capabilities: the human development approach*. Cambridge, MA: Belknap Press of Harvard University Press.

APPENDIX A

The Social Relationships of Adults with Serious Mental Illness Participating in a Church-Sponsored Day Program

Megan Smith, PI

Advisors: Dr. Molly M. Perkins and Dr. Ellen Idler

October 24, 2012

PARTICIPANT DEMOGRAPHIC INFORMATION

Interview Start Time _____ AM PM Interview End Time _____ AM
PM

First, I'd like to collect some general background information about you:

Please circle *one* number response for each question below.

1. Please record the gender of the participant:

_____ 1 Female
 0 Male

2. Are you of Hispanic or Latino origin?

_____ 1 Yes
 0 No

 998 Refused
 999 Don't know

3. What do you consider your race?

(Please record verbatim.)

RESPONSE CODE #3: (Please choose *one* answer.)

1 Black or African American
2 White or European Asian
3 Asian or Asian American
4 American Indian
5 Mixed or multiple races
6 Other _____

998 Refined
999 Don't know

4. What was your age on your last birthday?

_____ Total years

 998 Refused (*IF* and only if) participant refuses, offer
 them the range of ages listed in 4A)
 999 Don't know

4A. I have a list of age ranges. Can you tell me what age range you
 fall into?

_____ 1 18-44
 2 45-59
 3 60-64
 4 65-69
 5 70-74
 6 75-79
 7 80-84
 8 85-89
 9 90+

 998 Refused
 999 Don't know

5. Are you married, separated, divorced, widowed, or have you never been married?

_____ 1 Married
 2 Separated
 3 Divorced
 4 Widowed
 5 Never married
 6 Other

 998 Refused
 999 Don't know

6. What is your highest educational level?

_____ 1 Less than High School
 2 High School Graduate
 3 Some College
 4 College Graduate
 5 Post Graduate

998 Refused
999 Don't know

7. How would you rate your current physical health?

1	Excellent
2	Good
3	Fair
4	Poor

998 Refused
999 Don't know

8. How would you rate your current mental health?

1	Excellent
2	Good
3	Fair
4	Poor

998 Refused
999 Don't know

**The Social Relationships of Adults with Serious Mental Illness
Participating in a Church-Sponsored Day Program**

Megan Smith, PI

Advisors: Dr. Molly M. Perkins and Dr. Ellen Idler

April 11, 2012

INDIVIDUALS PARTICIPATING IN COMMUNITY-BASED DAY PROGRAM

PROGRAM STAFF DEMOGRAPHIC INFORMATION

Interview Start Time _____ AM PM Interview End Time _____ AM
PM

First, I'd like to collect some general background information about you:

Please circle *one* number response for each question below.

8. Please record the gender of the participant:

_____ 2 Female
 0 Male

9. Are you of Hispanic or Latino origin?

_____ 2 Yes
 0 No

 998 Refused
 999 Don't know

10. What do you consider your race?

(Please record verbatim.)

RESPONSE CODE #3: (Please choose *one* answer.)

7 Black or African American
8 White or European Asian
9 Asian or Asian American
10 American Indian
11 Mixed or multiple races
12 Other _____

998 Refined
999 Don't know

11. What was your age on your last birthday?

_____ Total years

998 Refused (*IF* and only if) participant refuses, offer
them the range of ages listed in 4A)
999 Don't know

4A. I have a list of age ranges. Can you tell me what age range you fall into?

_____ 2 18-44
2 45-59
3 60-64
10 65-69
11 70-74
12 75-79
13 80-84
14 85-89
15 90+

998 Refused
999 Don't know

12. Are you married, separated, divorced, widowed, or have you never been married?

_____ 2 Married
2 Separated
3 Divorced
4 Widowed
5 Never married
6 Other

998 Refused
999 Don't know

13. What is your highest educational level?

_____ 2 Less than High School
2 High School Graduate
3 Some College
4 College Graduate
5 Post Graduate

998 Refused

999 Don't know

14. How would you rate your current health?

2	Excellent
2	Good
3	Fair
4	Poor

998	Refused
999	Don't know

8. How would you rate your current mental health?

1	Excellent
2	Good
3	Fair
4	Poor

998	Refused
999	Don't know

Emory University
Consent to be a Research Subject

Title: The Social Relationships of Adults with Serious Mental Illness Participating in a Church-Sponsored Day Program

Principal Investigator: Megan Smith, a PhD student, Department of Sociology, Emory University; Advisors: Dr. Molly Perkins, Department of Medicine, Emory University and Dr. Ellen Idler, Department of Sociology, Emory University

Introduction

You are being asked to participate in a research project investigating clients' social relationships in a community based day program. This form is designed to tell you everything you need to think about before you decide to consent (agree) to be in the study or not to be in the study. **It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study. You can skip any questions that you do not wish to answer.**

Before making your decision:

- Please carefully read this form or have it read to you
- Please ask questions about anything that is not clear

You can take a copy of this consent form, to keep. Feel free to take your time thinking about whether you would like to participate. By signing this form you will not give up any legal rights.

Study Overview

The purpose of this study is to learn what kinds of social relationships clients of the Friendship Center have and how these relationships affect their daily lives. Knowledge gained from this study will inform those who develop policies and programs related to clients' quality of life in day programs designed for the mentally ill. This project is under the direction of Megan Smith, Dr. Molly Perkins and Dr. Ellen Idler. Approximately 100 clients, 5 staff members, 5 volunteers, and a director in a single program will participate in this project.

Procedures

If you choose to participate, you agree to let the researcher interview you in your facility. The researcher will ask you some questions about you and your experience with clients in the program. When you talk, the researcher may record your conversation. The interview will probably last one hour. If you become tired or uncomfortable and want to stop the interview at anytime, you may do so. You may also ask to have the recorder turned off for any part of the interview.

Risks and Discomforts

There is no known risk to participating in the study. Although you are not likely to receive any direct benefit, knowledge gained from this study may help professionals understand how to improve clients' quality of life in the day program.

Confidentiality

Your name will not be used in any way after the interview is finished, and all written interview records and general digital recordings will be stored in the locked office of the project principal investigator at Emory University. No one outside the research project will have access to this information about you, the participants, or the day program.

Voluntary Participation and Withdrawal from the Study

Participation in this research is voluntary. You do not have to be in this study. If you decide to be in the study and then you change your mind, you may stop your participation at any time. If you choose not to participate at all, or decide not to continue at a later time, it will have not have affected you in any way.

Contact Information

Contact Megan Smith at megan.smith@emory.edu or 404-333-3897

Dr. Molly Perkins at molly.m.perkins@emory.edu or 404-728-6570

Dr. Ellen Idler at eidler@emory.edu or 404-727-9148

- if you have any questions about this study or your part in it,
- if you have questions, concerns or complaints about the research

Contact the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or irb@emory.edu:

- if you have questions about your rights as a research participant,
- if you have questions, concerns or complaints about the research.
- You may also let the IRB know about your experience as a research participant through our Research Participant Survey at <http://www.surveymonkey.com/s/6ZDMW75>.

Consent

Please, print your name and sign below if you agree to be in this study. We will give you a copy of the signed consent to keep for your records.

Name of Subject

Signature of Subject
Time

Date

Signature of Person Conducting Informed Consent Discussion
Time

Date

IN-DEPTH INTERVIEW GUIDE FOR PARTICIPANTS

Researcher _____

Resident Code _____

Date _____

Interview Start Time _____ AM PM

Interview End Time _____ AM
PM

Demographic and Health Information

First, I would like to ask you some personal information and some questions about your physical and mental health and any needs you have for support from others.

[Use attached instruments to collect this information]

Early life and Middle Life

I would like to begin by learning a little about your earlier life.

Where born

Places of residence

Any history of homelessness, incarceration, substance abuse

Education- where attended elementary, high school, college, other

Biological family history

Siblings

Other important biological family members

Any marriages / children

Work history

Mental illness diagnosis (At what point in your life were you diagnosed? What impact did it have on your life at the time?)

Age of diagnosis

Has your mental illness affected your education? Work? Or social relationships?

Probes: education, work, social relationships

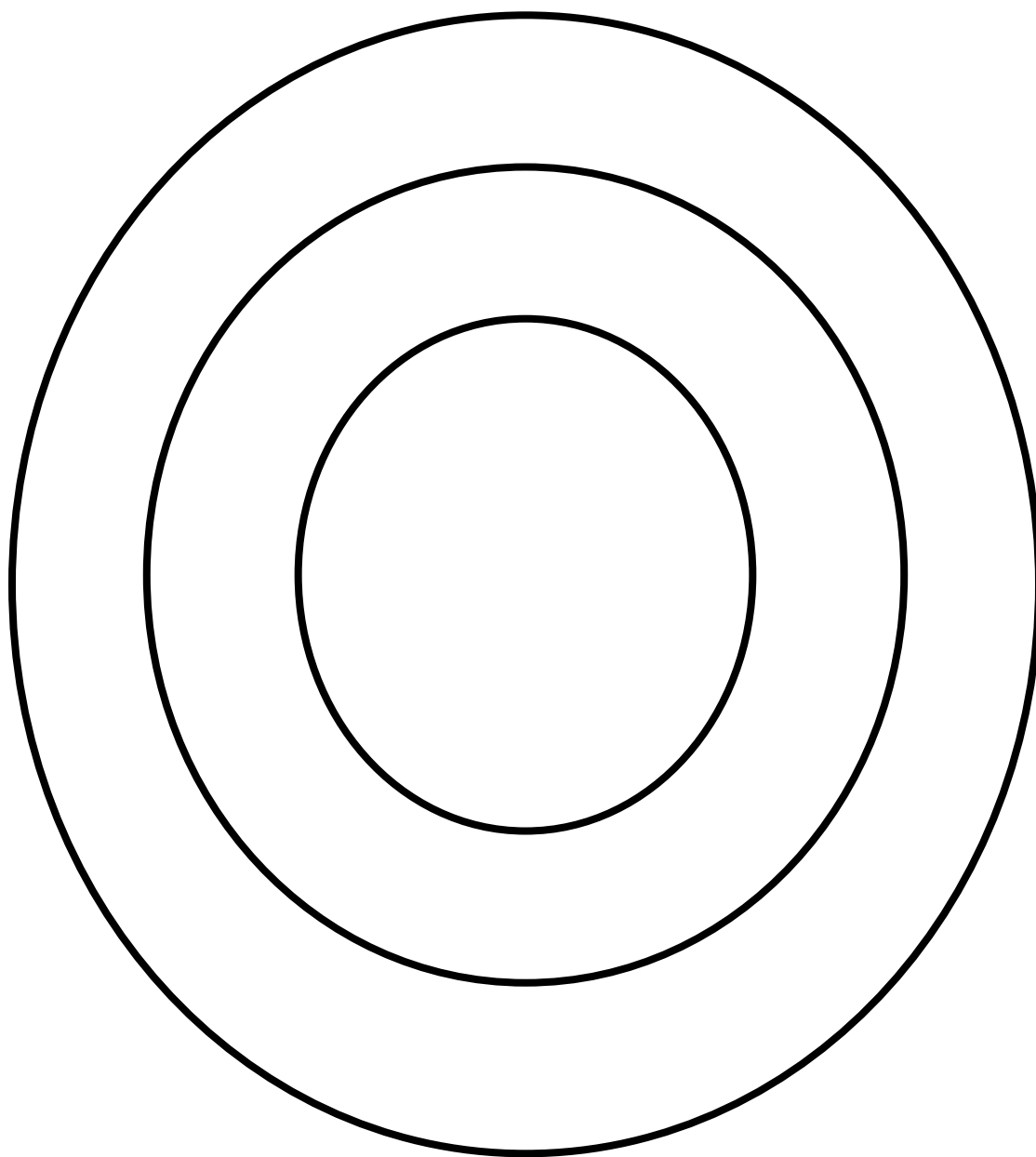
Social Support Network

Next, I'd like to learn about people you consider close to you and you can count on for help and support and have known at least a month. These people may be people you already have talked about and include family members, roommates or housemates, neighbors, or co-workers or even a doctor or other type of health care worker.

Present social network chart to patient and follow instructions for social network mapping.

NAME OF RESPONDENT: _____

DATE: _____





General Questions about Patient's Social Network

How many of these people live in your community\neighborhood?

Do many of these people know one another besides you?

Why did you list certain people in the circles that you did? (probe specifically for which circle)

Do you have a romantic relationship with anyone you have included on this map?

Probe for whether intimate relationship is casual, serious, recent, long-term (only probe for information not captured in demographic guide)

If patient did not include other participants or staff members from the center (i.e., from demographic chart) in his/her social network map, probe for reasons why they were not included.

For the first 10 people listed in the social network chart, probe for the following:

Now, I would like to learn a little more about your relationship with some of the people you have included in your map.

Can you talk to (use initials or nickname) about things that are very personal or private?

Is this someone you like to get together with and have fun with?

What types of activities do you engage in together?

Probe for activities that are health promoting as well as those that could be a risk to good health (e.g., smoking, drinking, recreational drug use).

If you needed to borrow money or something valuable, would this person help you out?

Is this someone you trust (i.e., to keep a secret, pay back a loan, etc.)

Is this someone you could ask advice about health problems?

Are you satisfied with your relationships with each of these people?

Do they provide you with life satisfaction?

I noticed that you did not list _____, but you spend a lot of time with _____ at the center. Why did you not list them in these circles?

Mediating Structures

Next, I'd like to switch gears and ask you about your experiences with The Friendship Center

Do you feel like you belong to the community of The Friendship Center?

What activities do you participate in at the center (probe for activities)

Do people invite you to participate or do you join in on your own

Some people refer to their ties to the community as giving them a sense of belonging to something bigger than themselves? Have you experienced this as a member of The Friendship Center or not?

I'm interested in any positive effects on your life that being a member of TFC might have. Has it better equipped you to fit into your community?

Has it made you feel stronger? In what ways?

(probe for living conditions, reduction in stigma, employment opportunities)

Religion, Meaning, and Coping

Next I'd like to ask you a couple of questions about your faith and mental health diagnosis

Does religion play a role in your life right now?

How do you explain your mental health diagnosis from a religious perspective?

In your opinion has God played any role in your diagnosis or recovery?

Can God heal your mental illness?

Does religion help you create meaning in your life? If so, in what ways?

Probe for what ways- some examples: art, activities, faith, relationships

Does religion facilitate relationships with other participants?

How so?

Probe for what ways- some examples: activities, worship, fellowship?

Does religion facilitate relationships with staff?

How so?

Probe for what ways- some examples: activities, worship, fellowship?

Conclusion

Finally, I'd like to ask some concluding questions.

Is there anyone that you would like to include in your social network map that you have not already included?

Are there any questions I asked that you would like to talk more about?

Is there anything I didn't ask that you wish I had?

Is there any other topic you would like to talk about that I didn't already ask you.

INTERVIEW GUIDE FOR STAFF

Researcher _____

Resident Code _____

Date _____

Interview Start Time _____ AM PM

Interview End Time _____ AM
PM

Demographic and Health Information

First, I would like to ask you some personal information and some questions about your physical and mental health and any needs you have for support from others.

[Use attached instruments to collect this information]

Job Characteristics

What is your position?

How long have you worked at the center?

Could you describe your responsibilities?

Staff Interactions/ Relationships with Participants

Now, I would like to ask a little about your own relationships with residents.

How would you describe your relationship with participants?

Differences for men and women

When do you typically interact with participants?

Could you describe these interactions

Can you tell me about any close/special relationships with residents?

What do you think led to this relationship?

Differences for men and women

Can you tell me about any negative or problem relationships you have with participants?

What do you think led to this relationship?

Differences for men and women

Has race affected your relationship with residents? (if applicable i.e., setting has diversity)
If yes, how?

Participants' Interactions/Relationships with Each Other

Now let's talk about participants' social relationships with other residents.

How well do you think participants know one another?

- Know each other's names
- Know personal information
- Differences for men and women

How would you describe their relationships with one another?

- Male/male relationships
- Male/female relationships
- Friendships? Conflict? Intimacy?

How important do you think residents' relationships with other participants are relative to other people in their social networks?

- Family members?
- Friends in the community?
- Program staff?
- Differences for men and women

When do participants spend time together?

- Differences for men and women

What kinds of activities do participants do together?

- Type of activity
- Which residents
- Where carried out
- Typical men's activities
- Typical women's activities
- Activities men and women do together

Where do participants usually spend time together?

- Why do you think that is?
- How does the physical lay-out of the campus influence participants' interactions with other participants?

Could you describe any help participants give to one another?

- Type of help
- Type of participant

How does helping affect relationships?
Differences for men and women

Can you tell me more about male/female relationships?
Are you aware of romantic relationships between residents?
Could you tell me about them?

What do you think promotes positive relationships between participants?

Why?

Differences for men and women

How do you think race and ethnicity influence participants' relationships with one another?

Differences for men and women

How does a resident's health status influence their relationships with other participants?

Probes:

Physical health

Mental health

Differences for men and women

How do you think having friendships with other residents affects residents' overall well-being?

Differences for men and women

How do you think having negative relationships with other residents affects participants' overall well-being?

Differences for men and women

How do you and other staff promote positive relationships between participants?

Get to know other participants

Make friends

Differences for men and women

How do you help participants manage their relationships with other participants?

Get to know each other?

Avoid unwanted interactions?

Differences for men and women

Mediating Structures

Next, I'd like to switch gears and ask you about your experiences with The Friendship Center

Do you feel like you belong to the community of The Friendship Center?

What activities do you participate in at the center (probe for activities)

Do participants invite you to participate or do you join in on your own

Do you feel ownership of Holy Comforter?

Does the center make you feel like you're part of something bigger than yourself?

Do you feel empowered to make changes in your community through your membership at The Friendship Center?

Do these changes involve reducing stigma about mental illness?

Do these changes increase employment opportunities?

Religion, Meaning, and Coping

Next I'd like to ask you a couple of questions about your faith and mental health diagnosis

Does you believe religion plays a role in the life of the participants?

How?

In what ways?

How does religion help create meaning in your life of participants?

In what ways?

Probe for what ways- some examples: helping build relationships, spending one-on-one time with participants

Does religion facilitate relationships with other participants?

How so?

Probe for what ways- some examples: activities, worship, fellowship?

Does religion facilitate relationships with staff?

How so?

Probe for what ways- some examples: activities, worship, fellowship?

Conclusion

Finally, I'd like to ask some concluding questions.

Are there any questions I asked that you would like to talk more about?

Is there anything I didn't ask that you wish I had?

Is there any other topic you would like to talk about that I didn't already ask you?

SOCIAL RELATIONSHIPS OF THE CHRONICALLY MENTALLY ILL OBSERVATION GUIDE

SUMMARY OF TOPICS (A detailed guide for each topic follows the summary)

- I. PLANNED NON-RELIGIOUS SOCIAL ACTIVITIES**
 - a. Programming: Art Therapy, Yoga, Bingo
 - b. Parties/ Events
- II. INFORMAL SOCIAL ACTIVITIES**
 - a. Smoking, talking in groups
 - b. Hanging out independently on campus
- III. MEAL TIMES**
 - a. Breakfast
 - b. Lunch
- IV. RELIGIOUS ACTIVITIES**
 - a. Attendance at religious services
 - b. Coping techniques
 - c. Activities facilitating meaning
 - d. Activities encouraging social interaction
- V. GUIDE for DESCRIBING OBSERVATIONS from IN-DEPTH INTERVIEWS**
- VI. GUIDE for DESCRIBING the PERSONAL CARE HOME PHYSICAL and SOCIAL ENVIRONMENT**
- VII. GUIDE for DESCRIBING COMMUNITY OUTSIDE PERSONAL CARE HOME**

I. PLANNED SOCIAL ACTIVITY

Researcher: _____

Date (include day of week): _____

Time: _____

Length of Observation: _____

Descriptive Notes:

Where does the activity occur? (at TFC or on the bus?)

What were the sequence of events ? (timing of events)

How is the activity introduced/ how does it begin?

Who is present at the beginning?

How long do specific events last? (e.g., Yoga lasts for 45 minutes)

What signals the end of the activity?

Who was involved in the activity?

Who stayed for the entire activity?

Who left? Why?

Who joined late? Why?

Who were the leaders?

Who just watched? Why?

Who needed help doing the activity? Who helped?

Describe the social environment:

How do people organize into groups?

What are the groupings like (e.g., all male groupings, all female)?

How do the participants relate to each other (e.g., how did males relate to females)?

How do they address each other?

How do participants arrange themselves in the social space? (diagram if necessary)

Describe the frequency and type of interactions? (e.g., how often does a participant engage in social interactions? With whom?)

Describe body language (gestures, people's expressions, etc.)

What do people say?

Do staff attempt to negotiate or manage participants' relationships with each other? If so, how?

Memos/Reflective notes:

II. INFORMAL GROUP ACTIVITIES

Researcher: _____

Date (include day of week): _____

Time: _____

Length of Observation: _____

Descriptive Notes:

Where does the activity occur?

What are the sequence of events? (timing of events)

How is the activity introduced/ how did it begin?

Who is present at the beginning? (e.g., do people arrive early for fellowship or to volunteer?)

How long do specific events last (e.g., participant volunteer activity like coffee service)

What signals the end of the activity?

Who is involved in the activity?

Who stayed for the entire activity?

Who left? Why?

Who joined late? Why?

Who initiated the activity?

Who just watched? Why?

How are things done?

How is the activity organized/or unorganized?

Who organizes the activity?

Is anyone excluded/not invited?

Describe the social environment:

How do people organize into groups?

What were the groupings like (e.g., all male groupings, all female)?

How do the participants relate to each other (e.g., how did males relate to females)?

How do they address each other?

How do participants arrange themselves in the social space? (diagram if necessary)

Do staff attempt to negotiate or manage participants' help with each other? If so, how?

Describe the type and frequency of interactions (e.g., how often does a participant engage in social interactions? With whom? How often do they volunteer? What volunteer activity do they engage in?)

Do staff attempt to negotiate or manage participants' relationships with each other? If so, how?

How do participants react to what was said/done?
 Describe body language (gestures, people's expressions, etc.)
 What do people say?

Memos/Reflective notes:

III. MEALTIMES

Researcher: _____
 Date (include day of week): _____
 Time: _____
 Length of Observation: _____
 Descriptive Notes:

Who is involved?

Describe sequence of events (timing of events)

Who arrives early for meals? Why?
 Who arrives late for meals? Why?
 Do participants arrive in groups or alone? Who accompanies whom?
 How long do meals last?
 Describe events that occur (e.g., distribution of meals, "seconds,"
 disruptions?)

Where do people sit for meals?

Do participants sit in different locations each time?
 How do residents decide where to sit, with whom to sit?
 Make diagrams
 Note changes in seating patterns
 Are any participants absent? Who notices if they are? What is said?

Describe the social environment:

How do the participants relate to each other (e.g., helping each other/ignoring
 each other)?
 Is there a lot of talking or are mealtimes quiet?
 Who talks to whom?
 How do participants address each other?
 What do people say?
 Do conflicts occur between participants? If so, what is said?
 Do staff attempt to negotiate or manage participants' relationships with each
 other? If so, how?
 Are staff attentive to participants' needs?
 Are other participants aware of other participants' needs? If so, what do they
 do?

Describe body language (gestures, people's expressions, etc.)

Memos/Reflective notes:

IV. RELIGIOUS ACTIVITIES

Researcher: _____

Date (include day of week): _____

Time: _____

Length of Observation: _____

Descriptive Notes:

Where does the activity occur?

What are the sequence of events? (timing of events)

How is the activity introduced/ how did it begin?

Who is present at the beginning? (e.g., do people arrive early for prayer or Bible study?)

How long do specific events last?

What signals the end of the activity?

Who is involved in the activity?

Who stayed for the entire activity?

Who left? Why?

Who joined late? Why?

Who initiated the activity?

Who just watched? Why?

How are things done?

How is the activity organized/or unorganized?

Who organizes the activity?

Is anyone excluded/not invited?

Describe the social environment:

How do people organize into groups?

What were the groupings like (e.g., all male groupings, all female)?

How do the participants relate to each other (e.g., how did males relate to females)?

How do they address each other?

How do participants arrange themselves in the social space? (diagram if necessary)

Do staff attempt to negotiate or manage participants' religious coping skills?

If so, how?

Describe the type and frequency of interactions (e.g., how often do participants talk to staff about religion? How often to staff initiate conversations about religion?)

Do staff attempt to negotiate or manage participants' relationships with each other? If so, how?

How do participants react to what was said/done?

Describe body language (gestures, people's expressions, etc.)

What do people say?

Memos/Reflective notes:

V. OBSERVATION GUIDE for IN-DEPTH INTERVIEWS

Researcher: _____

Date (include day of week): _____

Time: _____

Length of Observation: _____

Descriptive Notes:

Observations made prior to the interview.

Describe what you observed in the facility that day (same as general observation). Who was present?

What activities did you observe? Describe anything notable regarding the physical/social environment.

Describe events leading up to the interview: Was the interviewee on time?

Describe any problems encountered (e.g., finding a quiet space to conduct the interview, any interruptions). Describe the participant's demeanor, body language:

Was the participant nervous, anxious?

Events observed during the interview:

Describe any equipment/technical problems.

Describe any problems regarding the interview guide: Did the participant have difficulty answering any of the questions? If so, which ones?

Describe the participant's demeanor, body language: Was the participant nervous, anxious?

Did the participant hesitate or fail to answer certain questions?

Describe any information you gained that was not captured in the interview (e.g., asides, conversation preceding/following the interview)

Observations made after completing the interview:

Activities observed

Conversations with participants, etc.

Memos/Reflection Notes:

VI. OBSERVATION GUIDE for the PERSONAL CARE HOME ENVIRONMENT

(Ethnographic observation will inform environmental inventory)

Researcher: _____

Date (include day of the week): _____

Time: _____

Length of Observation: _____

Descriptive Notes:

Describe Personal Care Home Environment

Cleanliness/Dirty?

Attractiveness?

Well kept lawn or not?

Unpleasant odors?

Homelikeness

Social environment

Is the temperature comfortable?

Memos/Reflection Notes:

VII. OBSERVATION GUIDE for the COMMUNITY

Researcher: _____

Date (include day of week): _____

Time: _____

Length of Observation: _____

Descriptive Notes:

Accessibility Do residents have access to mass transit? How close is it Are there safe walking areas (e.g., free from crime, sidewalks that are not cracked) Note safety risks, such as presence of stray dogs running loose, heavy traffic, lack of street lights, and pedestrian signage, abandoned buildings, criminal activity, pan handling Are parks or other recreational activities nearby Are churches nearby? Are other community groups nearby?

Describe the homes, buildings on the street block Are the buildings all residential homes or is it a mix of homes and businesses Describe appearance of buildings, noting disrepair versus well-kept, note things like broken windows, graffiti, nice landscaping versus overgrown yards, litter, condoms, needles, cigarette butts, liquor bottles, beer cans New paint versus peeling paint Bars on windows? Boarded/burned down buildings

Describe local businesses (note appearance and upkeep) Small neighborhood shops and restaurants Liquor stores Bar and Taverns

Convenience stores Coffee shops Strip Mall Note any cultural or ethnic character (one-room African American church, corner store with Jamaican carry-out)

Describe the neighborhood social environment? Do neighbors sit outside/socialize from porches? Any noticeable public drinking, drug use, sex trade, homelessness? Children outside playing, people jogging, walking with strollers, walking dogs? Is there a noticeable police presence?

Describe observed interactions residents have with neighbors/other members of the community? Who initiates interaction?

What is the nature of the interaction?

Codebook**Location**

Common room
 Van Rides
 Picnic Tables
 Smoking Area
 Offices
 Library
 Garden
 Nursery
 WB-Art
 Property (on campus but not in another location)

Name Codes

*Individual names

Roles

Vicar
 Program Director
 Staff Member
 Volunteer
 Intern
 Gardener

Social Relationships

P & P (P=participant)
 P & V (V=volunteer)
 P & S (S=staff member)
 P & I (I=intern)
 V & S
 V & I
 S & I
 P & FM (FM=family member)
 P & MI (MI=other mentally ill)
 P & SP (SP=service provider)
 P & PCHA (PCHA=personal care home administrator)
 Lack
 Romantic
 Discord
 Support
 Lookout
 Desired (types of social relationships wanted)
 Loss
 Relationship (loss of relationship with living person)

Death
Distancing

Residence

PCH (PCH- L (licensed) & PCH- UN (unlicensed))
Independent
Family
The street
House
Apartment

Resides With

Family
Alone
Roommates

Transportation

Van rides
Walking
Bus
Train

Social Interaction

Social
Lack
Conflict
Sharing

Participant Characteristics

Education
Work History
Employment
Mental Health Status
Decline
Physical Health Status
Decline
Lifestyle (any reference to lifestyle behaviors)
Personal Values
Race/Ethnicity
Gender
Social Class
Age
Marital (current or past status)
Life Histories
Clothing
Hygiene

Poverty
Death

Staff Member Characteristics

Education
Work History
Employment
Mental Health Status
 Decline
Physical Health Status
 Decline
Lifestyle (any reference to lifestyle behaviors)
Personal Values
Race/Ethnicity
Life Histories
Gender
Social Class
Age
Marital (current or part status)
Life Histories

Volunteer Characteristics

Education
Work History
Employment
Mental Health Status
Physical Health Status
Lifestyle (any reference to lifestyle behaviors)
Personal Values
Race/Ethnicity
Life Histories
Gender
Social Class
Age
Marital (current or part status)
Life Histories

Intern Characteristics

Education
Work History
Employment
Mental Health Status
Physical Health Status
Lifestyle (any reference to lifestyle behaviors)
Personal Values
Race/Ethnicity

Life Histories

Gender

Social Class

Age

Marital (current or part status)

Life Histories

Mental Illness (includes descriptions and reference by participants, staff members, volunteers, or interns or in my personal reflections or memos)

Schizophrenia (any reference to disorder, including, actual wording, rhetoric, symptoms)

 Paranoid (reference to current or past mental health status or diagnosis)

 Psychotic (psychotic features, including delusions and hallucinations)

 Depressive (depressive features)

BPD (Borderline Personality Disorder) (reference to symptoms or diagnosis)

Anxiety (reference to emotion or diagnosis)

Depression (reference to emotion or diagnosis)

Bipolar disorder

 Psychotic (psychotic features, including delusions and hallucinations)

 Depressive (depressive features)

Memory (lapse and loss)

Hospitalizations (hospital name, length of stay, number of hospitalizations)

Mental Med

Other Day Programs

Physical Health

Phys Med

Disease

Diabetes

High Blood Pressure

Vitals

Decline

Blood Pressure

Routine Behavior

Seating Arrangements

Schedules

Meals

Programming

Art

Yoga

Reading

Writing

Bingo/Games

Gardening (?)

Religion

Bible study
Rhetoric
Am (prayer)
Noon (prayer)
Wed (Wed. service)
Sun (Sun. service)
Bible
Music
Prayer
Writing
Healing
Connection with participants
Connection with staff
Role in diagnosis
Role in recovery
Love
Meaning in life
Meaning of faith
Jesus

Research

Reflections
Memos

Caregivers

C-Formal
C-Informal (family, friends)

Scenario

Events
 Saturday Night Live
 Saturday Night Live Performance
Altercation (participant/participant, participant/other)

Sexual Encounters**Stigma****Organizational Characteristics**

Talking about
Referrals
Feelings about center closing
Life changes
 Housing

Employment
Stigma
Choice