

AN ETHNOGRAPHIC ANALYSIS OF STIGMA TOWARDS MENTAL ILLNESS AND
MENTAL HEALTH CARE AT CLUBHOUSES IN NORTH CAROLINA

Nikhil Tomar

A dissertation submitted to the faculty at the University of North Carolina at Chapel Hill in
partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Department
of Allied Health Sciences in the School of Medicine.

Chapel Hill
2018

Approved by:

Nancy Bagatell

Antoine L. Bailliard

Brian Boyd

Sue E. Estroff

Graham Thornicroft

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ABSTRACT

Nikhil Tomar: An ethnographic analysis of stigma towards mental illness and mental health care at Clubhouses in North Carolina
(Under the direction of Antoine L. Bailliard)

The purpose of this dissertation study was to identify the social processes guiding the experiences of stigma and occupational engagement (mental healthcare and community participation) for adults with serious mental illness. I employed an ethnographic approach to conduct this study. Aligned with the ethnographic approach, methods including interviews, fieldwork/participant observation, and document review were employed to collect data at two clubhouses in North Carolina. A total of eighteen adults with serious mental illness and sixteen clubhouse staff or service providers participated and their perspectives on the topics of interest, such as stigma and mental healthcare, were collected over a period of six months. Additionally, seven policy experts were interviewed to gather their perspectives on the influence of stigma on mental healthcare policies. Data were analyzed using open and focused coding along with analytic interpretation. The analysis led to generation of three papers that illustrate: 1) a social process (titled moral economics of occupations framework) conceptualizing occupations as assets and their relevance in maintaining institutional practices; 2) a conceptual framework highlighting the relationship between stigma, community participation, and mental healthcare policies; and 3) a social process (titled principle of gradient rationality) guiding experiences of stigma on an interactional level. Future research is required to assess validity and applicability of the proposed frameworks in different settings. Further, in order to address structural/institutional stigma, future research regarding marginalizing policies is required, as many adults with serious

mental illness continue to struggle due to systemic issues, such as incarceration, unemployment, poverty, and homelessness.

Keywords: stigma, ethnography, occupational engagement, community participation, mental healthcare policy

My aim is to put down on paper what I see and what I feel in the best and simplest way.
-Ernest Hemingway (Died by suicide in 1961)

This dissertation is dedicated to the histories that could have been.

ACKNOWLEDGEMENTS

I am forever indebted to the members and staff of Clubhouse Journey and Clubhouse Odyssey as they helped me not just in my career as a student researcher but the clubhouses were also a space that I could call my home away from home. In numerous ways, members' and staff's support and camaraderie helped me finish this doctoral degree.

Next, I am eternally thankful to Dr. Antoine L. Bailliard (dissertation chair), as without his support and guidance I would not have completed this dissertation. No amount of words can convey my gratitude for Dr. Sue Estroff, as through discussions with her I came to understand the importance of humility and an unquenchable thirst for knowledge. Like Dr. Bailliard and Dr. Estroff, I am also grateful to my dissertation committee members Drs. Nancy Bagatell, Brian Boyd, Sir Graham Thornicroft, and Mirja Koschorke (consultant) for their guidance. I am also thankful to Dr. Gary Cuddeback for his guidance and for providing me numerous opportunities to conduct and understand research. It is through the support and guidance of the entire dissertation committee and Dr. Gary Cuddeback that I now understand sentiment behind the statement: If I have seen further it is by standing on the shoulders of giants.

I am also thankful for support from my fellow doctoral students: Drs. Ashley Mason, Khalilah Johnson, Tyson Harmon, Mei-Ling, Todd Jensen, and Nelson Pace (former doctoral students), and Ben Lee. I learned from you as much as I learned from my books.

No words can describe my gratitude for the Royster Society of Fellows. The Fellowship program's financial and social support was integral for my growth as a researcher. Without the support from the society, I would have never experienced the bliss of research and teaching.

To my dear friends: Noorain, Lakshmi, Chetan, Neha, Beth, Eric, Nithya, Chris, Kim, Rachel, Kofi, Max, Gary, Keith, Chelsea, Taylor, Dimas, Susana, Peter, Sal, John, and Tuba, your support was my shield against numerous encounters with despair. I consider myself fortunate because of your friendships. I know these words will never fully convey my gratitude but know this: you were my home when I needed it the most.

Above all, I am very lucky to have the family that I have. Through their struggles, my father (Dilip Tomar) and mother (Pushpa Tomar) taught me that no dream can be achieved without struggle, and my biggest struggle to accomplish this doctoral degree was to live away from you for more than 7 years. This dissertation is as much an outcome of your struggles as it is of mine, and my only hope is that you are proud of this accomplishment. Finally, my dear brother (Akhil Tomar), your witticism has always been a reminder of the festivity that is life.

Thank you.

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CHAPTER 1: BACKGROUND AND PRIMARY PURPOSE

1.1 Introduction

The primary purpose of this dissertation study was to identify the social processes guiding experiences of stigma and engagement in occupations¹ (including community participation and mental healthcare) for adults with serious mental illness². This chapter briefly outlines the background for the study and describes the theoretical framework employed. This chapter also introduces the specific aims of the study. I conclude this chapter by briefly outlining the subject matter of the consequent chapters.

1.2 Background and Significance

The field of occupational science was brought into existence to study the construct of occupation and the processes related to occupational engagement and to generate evidence that provides theoretical support for the practice of occupational therapy (Clark et al., 1991; Yerxa, 1990). Since the field's inception, occupational science scholars have vigorously studied, debated, and discussed a variety of aspects related to occupations and occupational engagement, such as the relevance of context on occupational engagement and the relevance of occupation in addressing issues of social justice (e.g., Bailliard, 2016; Dickie, Cutchin, & Humphry, 2006; Hammell & Beagan, 2017; Townsend & Wilcock, 2004). Numerous scholars have also provided their perspectives on what an occupation is and how it can be defined (Royeen, 2002). As the

¹ Defined as participation in social acts, and thus, not conceptualized solely as engagement in employment.

² Serious mental illness is defined here as having diagnosis of a serious mental illness, such as psychotic disorders or major depression.

field continues to grow, scholars have also critiqued conventional wisdom or taken for granted assumptions that are employed to study or examine occupations and occupational engagement (Hammell, 2009; Hocking, 2000; Laliberte Rudman et al., 2008). For example, scholars continue to critique the influence of Western-based knowledge on the study of occupations and occupational engagement (Hammell, 2009; Hammell, 2014). The field is also brimming with sub-constructs related to occupation, such as occupational deprivation and co-occupation (Hammell & Beagan, 2017; Humphry & Thigpen-Beck, 1998; Pierce, 2009; Whiteford, 2000). While the field of occupational science is relatively nascent, it continues to grow and has a considerable knowledge base to defend its existence and maintain this growth. However, there are still numerous questions that are yet to be asked and numerous debates that are yet to be resolved.

Departing from the individualistic perspective on occupation, a transactional perspective provided guidance in steering occupational science towards a study of occupation and occupational engagement, where the context and the individual are equally valued (Dickie et al., 2006). Scholars continue to highlight the influence of various contextual factors (such as governmental policies) or constructs (such as agency) in guiding occupational engagement (Laliberte Rudman, 2012; Nyman, Josephsson, & Isakkson, 2013). Scholars continue to highlight the relationship between individuals and context, and its influence on occupational engagement via ideas related to various sub-constructs of occupation, such as occupational deprivation (Whiteford, 2000). Few authors have provided theories or frameworks on the relationship between individual and context (e.g., Crawford, Turpin, Nayar, Steel, & Durand, 2016; Law et al. 1996; Morris & Cox, 2017). However, the literature lacks frameworks or theories that comprehensively outline social processes guiding interaction between the individuals and the

context, using the unit of occupation (Whiteford & Hocking, 2012). Further, the existing models or frameworks give limited guidance regarding various aspects of occupational engagement, such as agency related to occupational engagement and influence of social capital on occupational engagement. Due to the lack of knowledge regarding social processes related to occupational engagement, there is inadequate evidence to address concerns related to occupational engagement of various vulnerable populations, such as adults with serious mental illness.

Occupational science scholars continue to study mental illness and its influence on occupations, including the impact of stigma (Blank, Harries, & Reynolds, 2015; Eklund, Hermansson, & Hakansson, 2012; Lin, Kirsh, Polatajko, & Seto, 2009). Occupational science scholars have primarily explored the influence of stigma on occupational engagement and the use of occupations to manage stigma through identity work (e.g., Blank et al., 2015; Laliberte Rudman, 2002; Nagle, Cook, & Polatajko, 2002; Segal, Mandich, Polatajko, & Cook, 2002). For instance, Blank and colleagues (2015) found that adults with mental illness used occupations to construct their identities as productive members of society and to manage stigma. However, there is a lack of evidence regarding the social processes that dictate occupational engagement of adults with serious mental illness. Since much of the occupational science evidence regarding the experience of mental illness and the stigma is descriptive, effective strategies to address concerns related to occupational engagement, such as community participation, are difficult to devise for this population.

For adults with serious mental illness, stigma is known to negatively influence community participation, which constitutes a significant aspect of their daily occupational engagement, such as employment (Link & Phelan, 2014; Sakiyama, Josephsson, & Asaba, 2010;

Sibitz et al., 2011; Thornicroft et al., 2009). There are around 10.4 million adults living with a serious mental illness in the United States (US), and many of them continue to experience challenges related to community participation, such as homelessness, unemployment, and/or incarceration (Luciano & Meara, 2014; Mechanic, Bilder, & McAlpine, 2002; SAMHSA, 2017; Torrey, Kennard, Eslinger, Lamb, & Pavle, 2010). Approximately, only 40% of adults with serious mental illness report being on full-time employment (Luciano & Meara, 2014; Mechanic et al., 2002). Concerns related to community participation are integral for this population since limited community participation deteriorates quality of life and can exacerbate psychiatric symptomatology (Burns-Lynch, Brusilovskiy, & Salzer, 2016; Kaplan, Salzer, & Brusilovskiy, 2012; Oliveira, Carvalho, & Esteves, 2015). It is important to note that challenges related to community participation are not solely related to psychiatric symptomatology as prevailing stigma significantly challenges community participation for adults with serious mental illness (Hinshaw & Stier, 2008; Pugh, Hatzenbuehler, & Link, 2015; Thornicroft et al., 2009). However, there is also a lack of evidence regarding the social processes that dictate experiences of stigma among adults with serious mental illness (Pescosolido & Martin, 2015; Thornicroft, Rose, Kassam, & Sartorius, 2007).

Evidence indicates that stigma involves ignorance, prejudice and discrimination towards a population that is deemed to have an undesirable attribute, such as a serious mental illness (Link & Phelan, 2001; Thornicroft et al., 2007). For example, prejudicial and stigmatizing attitudes among employers contribute to low employment rates among adults with serious mental illness (Baldwin & Marcus, 2011; Luciano & Meara, 2014; Mechanic et al., 2002; Stuart, 2006). While stigma research continues to grow, there are significant gaps in the literature that need to be addressed. First, there is a lack of consumers' perspectives regarding stigma, which limits

understandings of the social processes that guide experiences of stigma (Kleinman & Hall-Clifford, 2009; Thornicroft et al., 2007). Second, much of the stigma research has relied on survey research using a language of attributes (Pescosolido & Martin, 2015; Thornicroft et al., 2007). Due to an overreliance on surveys and a language of attributes, much of the research has ignored variability in adults who experience serious mental illness and the variability of stigma experiences on an individual level. Lastly, while scholars agree that there is a feedback loop between stigma at an individual and structural/institutional level, there is limited understanding regarding the social processes that maintain this feedback loop (Kleinman & Hall-Clifford, 2009; Pescosolido & Martin, 2015; Pugh et al., 2015; Thornicroft et al., 2007). Methodologically diverse studies that include consumers' perspectives to understand the social processes guiding experiences of stigma are urgently required. Thus, given the lack of evidence regarding the social processes related to occupational engagement and experiences of stigma, the primary objective of this study was to identify the social processes guiding experiences of stigma and occupational engagement (mental healthcare and community participation) for adults with serious mental illness.

1.3 Theoretical Framework

Since this dissertation is focused on the unit of occupational engagement, including community participation, it is important that I document my views regarding this unit. Using ideas regarding human action from Bourdieu (1998) and Cutchin and colleagues (2008), I conceptualize occupational engagement as participation in any social act or interaction via which habits/habitus and context are coordinated through action. Here the term social is not dependent on the number of people involved, as actions undertaken by an individual in a solitary situation are still social. For example, for a potluck, one may cook (an occupation) alone in a kitchen but

the occupation is primarily justified by its context of sharing food with others. Employing Bourdieu's (1998) ideas and drawing on the work of Cutchin and colleagues (2008), I argue that occupational engagement or participation is guided via interaction between habitus and context. Bourdieu (1998) proposed that human action is shaped by one's relative position in a social field, which can be defined as an arena of social interactions in which individuals develop or acquire their predispositions for action (or habitus). Per Bourdieu (1998), individuals compete for gains in social, economic, cultural, and symbolic capital in a social field. Capital in a social field can encompass a range of assets such as material assets (e.g., money) and cultural assets (e.g., academic credentials). In congruence with Bourdieu's ideas, I do not view action as purely self-interested behavior because actions are not taken through unrestricted agency and context guides human behavior (Bourdieu, 1998; Cutchin et al., 2008; Nyman et al., 2013). Accordingly, humans are intricately related to their past experiences and relationships such that these form the rationales and the social context for human actions (Bourdieu, 1998; Cutchin et al., 2008).

Further, I do not conceptualize the terms occupational engagement and participation as separate constructs or units (Royeen, 2002; World Health Organization, 2002). Evidence within occupational science suggests that participation is enacted via occupational engagement (e.g., Sakiyama et al., 2010; Steindl, Winding, & Runge, 2008). Due to the close relationship between the two concepts, it is difficult to conceptualize one without the other. Importantly, due to a lack of consensus regarding the definition of occupational engagement or participation, there is limited evidence regarding the explicit differences between the two concepts (e.g., Steindl, Winding, & Runge, 2008). Thus, for the purpose of this dissertation, I will be using occupational engagement and participation interchangeably.

In summary, I believe that occupational engagement is informed by past experiences as they form the rationalities that we employ, consciously and unconsciously, to undertake any act of participation or occupational engagement. Further, context (i.e., physical, cultural, historical, political) is an essential component for participation, as it guides an action, just like an individual does (Cutchin et al., 2008; Dickie et al., 2006). For example, an individual may not be able to cook for a potluck if there is no physical equipment, such as a cooking pot or stove, available. Similar to physical factors, a context also involves numerous social factors that affects human action, such as an individual's socio-economic position and/or social network. For example, one would not be cooking for a potluck if s/he did not have a social network that allows participation in a potluck.

1.4 Research Aims and the Core Chapters

The primary objective of this study was to identify the social processes guiding experiences of stigma and occupational engagement (mental healthcare and community participation) for adults with serious mental illness. In order to study the primary objective, three specific aims were undertaken: (1) identify consumers' perspectives on and experiences with stigma towards mental illness; (2) explore how stigma interferes with consumers' community participation, including engagement in mental healthcare, and (3) identify institutional factors that influence social interactions between consumers and service providers. Due to the ethnographic nature of the study, data collection in the field further informed the proposed specific aims. For example, during data collection, participants highlighted that a significant factor influencing clubhouse (a psychosocial rehabilitation model) interactions and community participation of consumers was mental healthcare policy. Therefore, the third aim was studied via the perspective of mental healthcare policies in the United States.

I have chosen to write this dissertation in a three-paper format. However, before documenting the findings I will present literature review in Chapter 2 focusing on 1) the current state of and research gaps in occupational science and stigma research, and 2) the influence of stigma on community participation for adults with serious mental illness. In Chapter 3, I outline the methodology and analytic strategies employed for this study and describe the research sites and participants' demographics.

The first chapter related to the findings, Chapter 4, will discuss the proposed moral economics of occupations framework, outlining a social process related to occupational engagement. In Chapter 5, I will discuss a conceptual framework that elaborates on stigma and its influence on community participation of adults with serious mental illness. Chapter 6 will elaborate on a social process guiding experiences of stigma, termed as the principle of gradient rationality. Finally, Chapter 7 describes the overall implications of the findings and their relevance for the stigma research and the occupational science/therapy scholarship.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

In the previous chapter, I briefly discussed the significance of this dissertation study. In this chapter, I provide a more detailed review of the existing evidence and highlight the research gaps relevant to the phenomena of interest, such as stigma towards mental illness and occupational engagement. I begin this chapter by discussing stigma towards mental illness and its influence on community participation. I then provide a critique of the existing evidence regarding stigma towards mental illness. Next, I elaborate on the occupational science literature and highlight the limitations present in the study of occupational engagement. I conclude the chapter by highlighting the relevance of this study.

2.2 Stigma towards Individuals with Mental Illness

Stigma as a social phenomenon has been fervently studied for more than half a century and has been a subject of scientific inquiry for various human situations and conditions, such as bankruptcy and obesity (Pescosolido & Martin, 2015; Puhl & Brownell 2003; Sullivan, Warren, & Westbrook, 2006). One of the most studied areas in stigma research is stigma towards psychiatric diagnoses or mental illness. With regards to mental illness, stigma has been studied for its conceptual make-up, its influence on behavior (e.g., healthcare utilization), on the self (e.g., self-esteem), on one's social life (e.g., social network), and to identify interventions to address it (Pescosolido & Martin, 2015). Briefly, stigma has been conceptualized as a social phenomenon involving ignorance, prejudice, and discrimination (Thornicroft et al., 2007). Ignorance and prejudicial attitudes towards mental illness contribute to labeling and stereotyping

of mental illness as a socially undesirable attribute, which leads to discrimination towards adults with mental illness (Link & Phelan, 2001; Thornicroft et al., 2007). Such prejudicial attitudes and discrimination negatively influence various aspects of community participation for adults with serious mental illness, such as social relationships and employment (Thornicroft et al., 2009).

2.2.1 Influence of Stigma on Community Participation

There is little doubt that humans are social/communal beings and that we maintain or improve our health and well-being via community participation³ (Axelrod, 1984; Herrmann, Call, Hernández-Lloreda, Hare, & Tomasello, 2007; House, Landis, & Umberson, 1988; Uchino, Cacioppo, & Kiecolt-Glaser, 1996). However, community participation continues to be a concern for adults with serious mental illness. There are approximately 10.4 million adults living with a serious mental illness in the United States (U.S.) and many of them continue to experience barriers to community participation, such as homelessness, unemployment, and/or incarceration (Luciano & Meara, 2014; Substance Abuse and Mental Health Services Administration [SAMHSA], 2017; Torrey et al., 2010; Housing & Urban Development, 2016). For example, in the US, there are three times as many adults with serious mental illness incarcerated in jails and prisons than receiving treatment in hospitals (Torrey et al., 2010). It is also estimated that in the U.S., 1 in 4 adults with serious mental illness are living below the poverty line (SAMHSA, 2016). Further, it is partly due to stigmatizing attitudes among employers that the high unemployment rate among adults with serious mental illness is sustained, as employers are likely to discriminate against this population (Baldwin & Marcus, 2011; Luciano & Meara, 2014; Mechanic et al., 2002; Stuart, 2006). Further, internalized-stigma, that is internalization of public

³ I conceptualize community participation as a domain of daily occupational engagement, as evidenced by Sakiyama and colleagues (2010), in the context of mental illness.

stigma among psychiatric consumers, negatively influences community participation (Oliveira et al., 2016; Yanos, Roe, Markus, & Lysaker, 2008; Yanos et al., 2012). For example, internalized stigma increases active social avoidance, which in turn reduces community participation (Oliveira et al., 2015; Yanos et al., 2008). Thus, due to the prevailing stigma, community participation is inevitably challenging for adults with serious mental illness.

Further, a lack of community participation adversely affects health and quality of life (QoL) outcomes for this population. The lack of adequate social relationships, support, and activities contributes to increased morbidity and mortality (Cacioppo & Cacioppo, 2014; Green et al., 2017; Liu et al., 2017). For example, living alone was found to be a significant predictor of mortality among adults with psychotic disorders (Keinänen et al., 2017). Lack of community participation also negatively influences psychiatric recovery (Burns-Lynch, Brusilovskiy, & Salzer, 2016; Kaplan, Salzer, & Brusilovskiy, 2012; Yanos et al., 2008). For instance: lack of engagement in employment and inadequate social relationships impedes psychiatric recovery (Burns-Lynch et al., 2016; Kaplan et al., 2012; Provencher, Gregg, Mead, & Mueser, 2002). Barriers to community participation are not solely related to psychiatric symptomatology. Prevailing stigma, both on an interactional and institutional level, contributes to challenges related to community participation (Link & Phelan, 2014; Thornicroft et al., 2009).

2.2.2 Limitations in Stigma Research

While the evidence adequately highlights the negative influence of stigma on various outcomes for adults with serious mental illness, such evidence is primarily descriptive and provides limited understanding regarding the social processes that dictate experiences of stigma (Estroff, Penn, & Toporek, 2004; Kleinman & Hall-Clifford, 2009; Pescosolido & Martin, 2015; Thornicroft et al., 2007). The contemporary ideas of describing stigma using a language of

attributes and highlighting mental illness as an undesirable social attribute are remnants of Goffman's (1963) ideas regarding stigma (Link & Phelan, 2001; Pescosolido & Martin, 2015; Thornicroft et al., 2007). However, while Goffman (1963) defined stigma using a language of attributes, he was clear that a language of relationships is ultimately required to understand the social processes related to stigma. Further, because it relies on a language of attributes related to mental illness, such as unpredictability and dangerousness, present stigma research is steeped with survey-based research examining stigma via attitudinal assessments (Pescosolido & Martin, 2015; Thornicroft et al., 2007). While survey methodology allows for assessing stigma via a language of attributes, an overreliance on surveys limits understandings of social processes related to stigma and yields evidence that is derived via methodologically non-diverse studies (Kleinman & Hall-Clifford, 2009; Thornicroft et al., 2007). Additionally, very few survey studies employ safeguards against or account for social desirability within participant responses while assessing stigma, thereby leaving findings vulnerable to flawed estimations of stigma and preserving conceptual limitations (Corrigan, Bink, Fokuo, & Schmidt, 2015; Fowler, 2013; Pescosolido & Martin, 2015; Thornicroft et al., 2007). Another limitation plaguing stigma research is a lack of perspectives regarding stigma from mental healthcare consumers, which further limits evidence related to experiences of stigma (Pescosolido & Martin, 2015; Thornicroft et al., 2007). Notably, evidence regarding perspectives from mental healthcare consumers and efficacy of existing interventions to address stigma in low or middle income countries is severely limited, challenging global mental healthcare efforts (Semrau et al., 2015; Thornicroft et al., 2016). Due to such limitations, existing evidence provides limited guidance to address stigma on both a personal as well as on a community level, on a global scale (Estroff et al., 2004; Mehta et al., 2015; Pescosolido & Martin, 2015; Pugh et al., 2015; Thornicroft et al.,

2016). Further, existing interventions addressing stigma such as psychoeducation and contact strategies are limited in their long-term influence on reducing stigma (Mehta et al., 2015). Thus, methodologically diverse studies of stigma are required to adequately include consumers' perspectives to better understand the social processes guiding experiences of stigma.

Further, due to an inadequate understanding of stigma, there are also limitations that impede addressing stigma at a structural or policy level. Various scholars have provided theoretical or conceptual frameworks connecting structural- and individual-level stigma (e.g., Pescosolido, Martin, Lang, & Olafsdottir, 2008), and there is agreement among scholars that a feedback loop between stigma at an individual- and structural-level exists (Corrigan, Markowitz, & Watson, 2004; Link & Phelan, 2001; Link & Phelan, 2014; Pescosolido et al., 2008; Thornicroft et al., 2007). However, there is a lack of clarity on operationalizing structural stigma in order to understand and examine the social processes and tools (such as policies) that sustain it (Pescosolido & Martin, 2015; Pugh et al., 2015). There is also a lack of research that explicitly analyzes mental healthcare policy from the standpoint of stigma towards mental illness (Pescosolido & Martin, 2015; Pugh et al., 2015; Thornicroft et al., 2007). One of the few studies existing within this realm evaluated policies and found that multiple legislative bills restricted liberties (such as rights related to refusing treatment) of adults with mental illness (Corrigan et al., 2005). Finally, there are also very few studies that include policy experts' or stakeholders' perspectives regarding structural stigma and the relevance of stigma in mental healthcare policy decision-making. Limited understanding regarding the role of stigma on mental healthcare policy decision-making hinders gathering the evidence required to address structural stigma, on a policy level. Thus, there is an urgent need for generating evidence regarding social processes that

maintain structural stigma in the arena of mental healthcare policy, which can limit community participation for adults with serious mental illness.

2.3 Occupational Science and Stigma

Occupational science scholars continue to study mental illness and its influence on occupations, including the impact of stigma (Blank, Harries, & Reynolds, 2015; Eklund, Hermansson, & Hakansson, 2012; Lin, Kirsh, Polatajko, & Seto, 2009). Research within occupational science has demonstrated that stigma is a barrier to occupational engagement among mental healthcare consumers (Nagle, Cook, & Polatajko, 2002; Segal, Mandich, Polatajko, & Cook, 2002). For example, Sakiyama and colleagues (2010) found that adults with mental illness report difficulties in occupations engagement partly due to the prevailing stigma. Similar to Goffman's work on stigma, occupational science scholars have also studied stigma in relation to identity construction and management (Blank et al., 2015; Laliberte-Rudman, 2002). For example, Blank and colleagues (2015) found that adults with mental illness managed stigma by engaging in vocational occupations to construct their personal and social identities as productive members of society. However, in the occupational science literature, stigma has rarely been explored as a focal aspect of the lived experience of adults with serious mental illness. For instance: while Sakiyama and colleagues (2010) described community participation among consumers, they only briefly mentioned the negative influence of stigma on their occupations.

Limited scientific understandings of stigma through an occupational lens also refrains from understanding stigma as a sociological force influencing the life experiences and occupations of any individual who can be labeled as a social deviant. Using an occupational lens to understand the social construction of deviance and the experiences of

marginalization/discrimination of populations that are often deemed as social deviants is critical in expanding the role of occupational justice⁴ in larger scholarly arenas. The lack of occupational science scholarship on stigma has also limited understanding of how stigma changes human behavior in various contexts. For instance, public health strategists have harnessed stigma as a tool to change behaviors related to smoking (Bell, Salmon, Bowers, Bell, & McCollough, 2010). Occupational science, due to its limited study of stigma, has an inadequate understanding of how stigma influences human occupations, actions, and conditions. Such evidence can propel understandings of occupation itself as occupational science scholars continue to illustrate the influence of social and contextual forces in influencing occupational engagement and the injustices related to occupational engagement.

2.3.1 Critiquing Occupational Science

A significant portion of occupational science scholarship focuses on understanding the construct of occupation (Clark et al., 1991; Hocking, 2009). Initially occupations were studied through an emphasis on individualistic perspective; currently, however, there is wider agreement that occupations are not individualistic and that context or environment guides occupational engagement, similar to individual actions (Cutchin et al., 2008; Dickie et al., 2006; Morris & Cox, 2017; Royeen, 2002). Further, as scholars continue to debate regarding occupational engagement, the field is brimming with sub-constructs related to occupation, carrying over various assumptions about occupations and/or occupational engagement (Hammell & Beagan, 2017). For example, multiple sub-constructs related to occupational injustice exist, such as occupational imbalance and occupational alienation; however, these concepts carry forward various assumptions, such as Western neoliberal expectations for occupational engagement or

⁴ Occupational justice has been defined as “equitable opportunity to enable people’s engagement in meaningful occupations” (Wilcock & Townsend, 2000, p. 85).

participation, regarding the construct of occupation, and there is a lack of empirical evidence regarding the conclusive definitions and influences of these sub-constructs (Durocher, Rappolt, & Gibson, 2014; Hammell & Beagan, 2017).

Further, various occupational science scholars have promoted the idea that occupations exist within value systems that guide occupational engagement (Angell, 2012; Laliberte Rudman, 2012; Nyman et al., 2014; Persson, Erlandsson, Eklund, & Iwarsson 2001). As occupations are situated within a socio-cultural context, occupations inevitably exist within a value system that maintains the hierarchical and situated nature of occupations (Angell, 2012; Galvaan, 2015; Laliberte Rudman & Huot, 2013; Madsen & Jossephson, 2017; Prodinge, Laliberte Rudman, & Shaw, 2015; Ramugondo & Kronenberg, 2015). However, despite these advances in understanding the hierarchical and situated nature of occupations, there is a paucity of evidence to better understand the social processes that explain the situatedness of occupations and its role in maintaining social hierarchies (Prodinge et al., 2015; Whiteford & Hocking, 2012).

In occupational science, an ultimate goal for examining the power relationships and situatedness of occupations is to address concerns of occupational justice or injustice and change institutional policies/practices and to improve the lives of those experiencing marginalization and discrimination (Hammell & Beagan, 2017; Laliberte Rudman & Forwell, 2013; Pereira, 2014; Urbanowski, Shaw, & Chemmutter, 2013). Scholars have highlighted the influence of various factors, such as governmental practices, on maintaining injustices related to occupational engagement (Laliberte Rudman, 2012). However, the current scholarship provides little guidance regarding the social processes that allow injustices related to occupational engagement to exist and continually embed themselves as undisputed normative practices (Hammell & Beagan, 2017;

Hocking & Whiteford, 2012). It is unlikely that issues related to the occupational engagement of marginalized populations can be effectively addressed if we, as occupational science scholars, do not understand the social processes that allow sustenance of occupations as vehicles for both sustaining and dismantling social discrimination and marginalization (Angell, 2012; Bailliard, 2016; Hammell & Beagan, 2017). For example, in order to address discriminatory employment practices against adults with mental illness, one has to understand the social process guiding the occupational engagement for a potential employee who is discriminated/stigmatized because of his/her serious mental illness, and an employer who believes that an individual with serious mental illness cannot successfully participate in an advertised occupation (Baldwin & Marcus, 2011). Thus, the disconnect between the aspirations of occupational science scholars and the inadequate availability of evidence for scholars to fulfill those aspirations limits the reach of occupational science to critically examine the unit of occupation and go beyond its own disciplinary boundaries.

2.4 Conclusion

In occupational science, there is a gap in scientific understanding regarding the social processes related to occupational engagement and stigma towards mental illness. The primary purpose of this study is to identify the social processes guiding experiences of stigma and engagement in occupations (community participation and mental healthcare) for adults with serious mental illness. The literature reviewed above helps bolsters the need for this study by highlighting the gaps in the literature regarding the phenomena of interest for this dissertation. The following chapter will discuss the methodology and methods utilized to study the gaps identified above.

CHAPTER 3: METHODS

3.1 Introduction

In this chapter, I will elaborate on the methodology and the methods that I employed to collect and analyze data for this study. I will begin with my rationale for employing ethnography as the methodology for this study and then describe the methods used for data collection (Table 1). Later, I will elaborate on the research sites and the participants included in the study. I will conclude the chapter by describing the data analysis strategies used for this study.

Table 1. Data collection overview

Methodology	Ethnography
Methods	Interviews, fieldwork/participant observation, and document review
Sampling	Purposive/Convenient/Snowball
Recruitment	Announcements in the clubhouse and assistance from the clubhouse staff and members (adults with serious mental illness)
Research sites	Two clubhouses located in a southeastern state in the United States
Sample size and participants	N=18 clubhouse members N=16 clubhouse staff or providers N=7 policy experts

3.2 Ethnography

Scholars in anthropology and sociology are credited for the emergence of ethnography as a research methodology (Adler & Adler, 1987). Stemming from qualitative research, ethnography follows an inductive approach to explore a phenomenon of interest and can be employed to generate or refine theories, frameworks, or concepts (Estroff, 1981; Katz, 2001;

Snow, Morrill, & Anderson, 2003). As a methodology, ethnography is an exploration of everyday behaviors, interactions, relationships, and ways of living of a group, to understand the social processes that undergird a phenomenon, a culture, or an institution (e.g., participation in a clubhouse as a culture) (Adler & Adler, 1987; Creswell, 1998; Snow et al., 2003; Willis & Trondman, 2005). Conducting an ethnography requires gathering perspectives from individuals who are intimately involved or connected with the phenomenon of interest and collecting information on their everyday experiences via observations (Creswell, 1998; Snow et al., 2003). Thus, as the primary objective of this dissertation was to explore the social processes guiding experiences of stigma and its influence on occupational engagement by gathering participants' perspectives, ethnography was chosen as the methodology for this study.

During early ethnographic works, scholars used this methodology to explore experiences of cultural groups that were either not in the vicinity of or occupied a non-normative locale in contemporary Western society (Becker, 1967; Katz, 1997). Many of the early ethnographic texts explored lived experiences of groups that were labeled as social deviants, such as marijuana users (Becker, 1963). Ethnography has also been used to examine the context and actions of others that help sustain the social systems/processes perpetuating discrimination and marginalization of groups labeled as social deviants (Adler & Adler, 2007; Katz, 1997; Sercu & Bracke, 2016). Thus, ethnography allows a researcher to uncover both the social rules of participation operating within a group (including those that are labeled as social deviants), and the social processes that create the group differences of “us” and “them” (Becker, 1963; Katz, 1997). Since the objective of this dissertation was to better understand the social processes related to the occupational engagement of adults with serious mental illness who occupy the social space of “them” or “other” or “stranger,” ethnography was an appropriate methodology

(Baumann, 2007; Corrigan, Edwards, Green, Diwan, & Penn, 2001; Link & Phelan, 2001; Link & Phelan, 2014).

Besides studying the situatedness or experiences of non-normative groups and behaviors, other reasons to conduct ethnography include: studying historically emergent social phenomena (e.g., stigma and mental healthcare), the need to elicit narratives from social groups (e.g., the perspectives of psychiatric service users on stigma and occupational engagement), and exploring the influence of or recommendations for policy (e.g., exploring influence of policies on community and mental healthcare engagement)⁵ (Katz, 1997). I chose to employ ethnography, as the aforementioned aims of this methodology fit well with the primary purpose and aims of this research.

Ethnography also provides a researcher an opportunity to analyze the data in ways that are beyond descriptive. As I argued in the previous chapter, the theoretical limitations that scar contemporary enquiries regarding stigma (such as the lack of mental healthcare consumers' perspectives regarding social processes that guide their experiences of stigma) required an understanding of stigma that could address those theoretical limitations. Ethnography allows for data to be interpreted in a way that can help in theory development and/or refinement (Snow et al., 2003). Through engaged fieldwork, in-depth interviews, document reviews, and other methods, ethnography provides an opportunity for an interpretive account that allows unearthing social processes that exist in the data collection field (Daly, 1997; Snow et al., 2003). For instance, Goffman's (1961) *Asylums: Essays on the social situation of mental patients and other inmates* or Becker's (1963) *Outsiders: Studies in the sociology of deviance* are ethnographies that put forth ideas that continue to undergird the contemporary research on social deviance.

⁵ Literature review regarding the aspects mentioned here, such as lack of perspectives from mental healthcare consumers, has been elaborated on in the previous chapters.

Like any other methodology, ethnography has limitations. Ethnography does not allow for hypothesis testing, quantitative predictions or the generalization of findings (Daly, 2007; Denzin & Lincoln, 1994). Ethnography relies on how a researcher understands a phenomenon based on his or her observation. This study involved two clubhouses and one researcher. Therefore, there were certainly sets of events that were missed, which may have altered the course of the research. To account for such limitation, I ended data collection when similar perspectives started to emerge from interviews and participation observation on a regular basis; that is, when data saturation was reached (Fusch & Ness, 2015).

3.3 Ethnographic Access

One of the challenging aspects of an ethnography is to gain entry into the ethnographic field or the culture or institution that a researcher intends to explore. My fieldwork took place at two clubhouses⁶ (psychosocial rehabilitation model) in North Carolina: Clubhouse Journey and Clubhouse Odyssey (pseudonyms). I had been a volunteer/research student at Journey for around 18 months before I formally began my dissertation data collection there. My first entry at Journey was in January 2015, through an independent study course regarding stigma towards mental illness. Via the course fieldwork at Journey, I gathered knowledge that helped me critique the contemporary stigma research and rationalize a dissertation project with the purpose of examining social processes related to stigma experiences. Further, due to my past participation at Journey, I had established enough social relationships that my entry as a doctoral research student was rarely problematic. Further, advantages of past experience at Journey were not limited to engagement at this site only.

⁶ I will expand on the clubhouse model later in the chapter.

As I was familiar with the culture of the clubhouse model via my participation at Clubhouse Journey, interacting with members and staff at Clubhouse Odyssey was rarely challenging. While I acknowledge that the two clubhouses are different in various aspects (such as architecture/social geography), it was helpful that both operated with similar practices that are consistent with the clubhouse model. Further, recruiting and establishing rapport with staff personnel at both the clubhouses was rarely challenging as the staff were interested to be part of the study. Many staff agreed to participate in the study as they hoped to better understand stigma and strategies to address it so that they can further enhance member participation at the clubhouses and in the nearby communities. Further, I often framed my role as a learner trying to understand stigma towards mental illness and occupational engagement, instead of a researcher who is there to extract data. Adapting the stance of a learner helped establish a rapport with the staff and members alike.

3.4 Reflexivity

While my previous experience at a clubhouse was helpful, being an immigrant was simultaneously helpful and disadvantageous. From the outset, I understood the challenges and advantages of ‘being brown’ while trying to gain entry to clubhouses in the American South. As a brown immigrant (who has been in the United States for around seven years), I had not had the opportunity to fully understand American cultural practices. However, clubhouse members and staff routinely assisted me in understanding traditional American culture. At several occasions, study participants took the time to inform me about various cultural idioms (such as “a stitch in time saves nine”) that I did not immediately understand. Further, my foreign appearance incited curiosity among various participants. It was helpful when people asked me questions about the Indian culture as our conversations would eventually lead to questions like “why are you here?”,

which helped in participant recruitment, as the answer led to discussions regarding this study.

There were also multiple times when my accent was a hurdle for communication. However, the participants (members and staff) and I felt comfortable in asking clarifying questions.

There were also times when my color or the immigrant status became a proxy for cultural inferiority. For example, a member once asked me if Indian “culture is civilized and has electricity.” I smiled and informed him about India and Delhi - the city where I grew up. Later in my fieldwork, the same member informed me about his perspectives on psychiatric hospitalizations. Thus, even moments of conflict arising via ill-informed perspectives, which were far outweighed by genuine curiosity among participants, led to the development of fruitful and pleasant relationships.

Further, being different was also an advantage that, ironically, helped me to blend in. More than once during my fieldwork, I was mistaken as a member or asked “are you a member?” For example, more than once, a member, who routinely manages the reception desk of Clubhouse Odyssey, gave me the member sign-in sheet to document my entry. Such instances, again, led to conversations regarding the dissertation study and assisted in establishing relationships and participant recruitment.

I did not have any difficulties in establishing relationships with staff. As I would come to find later, staff care deeply about members. Staff at both clubhouses were very supportive of this dissertation project and almost every staff that I approached for recruitment agreed to participate.

3.4.1 Thinking about Stigma

My curiosity towards the constructs of stigma and occupation was the primary impetus to undertake this project. My understanding of these constructs and their conceptual make-up emerged, primarily, from the research literature that I read during the course of my doctoral

degree. Prior to entering the doctoral program, I had rarely read research regarding stigma. During the beginning of my doctoral studies, my interest in stigma was to explore the construction and implication of the stigmatizer-stigmatized relationship. However, this initial focus led me to mistakenly categorize a heterogeneous population of identities and behaviors under the homogenous labels of stigmatized and stigmatizer. With this erroneous perspective, everyone with a psychiatric label became a stigmatized person who needed advocacy while others became stigmatizers whose prejudices needed to be exposed. Consequently, I came to see the implications of stigma as a situation of conflict that needed to be successfully mediated. Later in the course of my degree, I discovered the limitations of my assumptions and biases through an independent course regarding stigma towards mental illness.

During the independent study/course, I volunteered/interned at Clubhouse Journey for approximately 8 months in 2015. Through my experiences at the clubhouse I discovered my assumptions/biases regarding the overly simplistic notion of the stigmatizer-stigmatized dichotomy. At the clubhouse, I engaged in ethnographic fieldwork to understand stigma and its conceptualization among the members. Through my fieldwork, it became evident that the neat labels of stigmatizer and stigmatized were not absolute but situational and embedded in the context of relationships. For example, during one moment a member (adult with serious mental illness) can be stigmatized by a community member and at another moment the same member can stigmatize another member for their non-normative behavior. My fieldwork highlighted that stigma manifests in the implicit operations of relationships instead of through a seemingly fixed language of attributes. Thus, throughout the dissertation data collection, I put forth conscious efforts to understand the relationships and interactions in order to understand stigma and its social processes.

3.5 Research Sites

Two clubhouses, Journey and Odyssey (pseudonyms), were chosen as data collection sites. Due to my previous research engagement and the dissertation's focus on assessing stigma and community participation or occupations, the clubhouse model was chosen as a logical and pragmatic research site.

The study was approved by the Institution Review Board at University of North Carolina-Chapel Hill (IRB#16-2920).

3.5.1 The Clubhouse model

Clubhouses are non-profit psychosocial rehabilitation settings organized to support adults with serious mental illness, referred to as members. Members spend the daytime at the clubhouse and work with staff as colleagues to undertake tasks, such as preparing food and writing grants to sustain the clubhouse (Corcoran, 2013). Various support services, such as transitional employment and opportunities to complete formal education, are provided at a clubhouse. Although clubhouses do not provide any formal healthcare services, staff does assist members in accessing healthcare services by providing transportation or establishing contacts with healthcare professionals. The model is included in the Substance Abuse and Mental Health Services Administration's registry for Evidence-Based Practices (SAMHSA, 2015).

Clubhouses are intentionally under-staffed so that members have opportunities to contribute to daily activities or tasks. At the heart of a clubhouse's functioning lies the meaningful relationship between staff and members. A clubhouse works on a horizontal hierarchy, where members and staff participate in collaborative decision-making regarding its various operations. No staff-only or member-only meetings are held at a clubhouse. However, there is an understanding that staff and member roles are "not interchangeable in the clubhouse"

(Vorspan, 2004, p. 2). In the next section I provide some detailed information of the clubhouses where I undertook my observations.

3.5.2 Clubhouse Odyssey

Clubhouse Odyssey is located in Carmon county (pseudonym) of North Carolina. National estimates suggest that, as of 2015, Carmon county has a population of around 290,000⁷. Slightly more than half of Carmon county residents identify as White, while around one-third identify as Black or African-American, and the rest identify as Hispanic or Latino, or Asian (United States Census, 2015). Around 20% (national average at 14.7%) of individuals live below the poverty line in the county (United States Census, 2015). A Point-in-Time count survey in Carmon county revealed that around 15% of the adults experiencing homelessness reported experiencing serious mental illness (North Carolina Coalition to End Homelessness [NCCEH], 2015).

Unlike Journey, Odyssey is located in a low-income neighborhood. During my walks around the clubhouse neighborhood, it was not uncommon to see broken bottles on the sidewalk, houses with broken windows, cars with cardboards as windows, and caged dogs in backyards. During one of my walks, a member told me that he feels safer when somebody is walking with him during organized afternoon clubhouse walks.

Clubhouse Odyssey is situated in an old church building and has a hallway connecting all rooms, with a big meeting/dining room at the end of the hallway. Odyssey is bigger in size than Journey and that size difference did contribute to differences in usual routines of both staff and members at the two clubhouses. Odyssey has five units: culinary, snack bar, membership, transitional employment and education, and administration. There is a kitchen and a snack bar in

⁷ To prevent deductive disclosure, precise figures regarding county demographics are not provided.

the clubhouse along with a library room and the great room (meeting space). The clubhouse also has a small garden and a back porch, where members are allowed to smoke. There is also an administrative unit room where many members “hang out” with other members and staff or use computers.

3.5.3 Clubhouse Journey

Clubhouse Journey is a clubhouse located in Woodward county (pseudonym) of North Carolina. National estimates suggest that, as of 2015, Woodward county has a total population of around 140,000. The majority (approximately 75%) of Woodward residents identify as White while rest of the residents identify as Black or African-American, Hispanic or Latino, or Asian (United States Census, 2015). In 2015, around 15% of individuals reported living below poverty line (national average was 14.7%). A Point-in-Time count survey in Woodward county revealed that around 30% of adults experiencing homelessness in the county reported having serious mental illness (NCCEH, 2015).

There are two buildings that comprise Clubhouse Journey. The main building houses the kitchen, membership unit, a small snack bar and a small meeting room while the other building houses a thrift store and the administrative unit. Members work in different units throughout their work-order day, such as the thrift store, the kitchen, or the administrative unit. Unlike Clubhouse Odyssey, Clubhouse Journey is situated in an economically thriving community. There are numerous public parks and shopping complexes including a community-owned natural foods grocery store nearby.

During the study period, Clubhouse Journey and Odyssey had an active membership of 104 and 88 members, and on average 32 and 19 members participated there on a daily basis, respectively. Both clubhouses are near shopping complexes that house grocery stores,

restaurants, coffee houses, and other shops, providing accessible avenues for shopping and transitional employment for members. The clubhouses also have vans that are used to assist members in transportation. The clubhouses are primarily funded via Medicaid billing that is disbursed through managed care organizations (MCOs). Accurate data regarding the overall incidence of serious mental illness was not available for either counties.

3.5.4 Work-Ordered Day at Journey and Odyssey

Work-ordered days at the clubhouses begin with a morning meeting. During the morning meetings, members and staff collectively discuss their tasks for the day and duties are assigned. Generally, a member is responsible for heading these meetings. During the meeting, members choose tasks or occupations that they would like to accomplish and any important news (such as upcoming birthday celebrations or community tours) is shared. Both clubhouses used white boards, situated in the meetings rooms and in other units as well, to list their daily tasks and individuals responsible for those tasks. Usually, in both clubhouses, certain members choose to do specific tasks on a regular basis. For example, at Clubhouse Odyssey, William almost always chose to empty out the trash bins. After the morning meeting, both staff and members transition to their daily tasks. Daily tasks for staff mostly related to their job responsibilities. For example, an administrative unit staff would work on his or her computer to accomplish administrative duties. Since the clubhouse model is not based on conventional clinical model, the staff would frequently engage members in their routine tasks. For example, an administrative unit staff might ask members to look at the member sign-in sheets to document hours during which members were present in a clubhouse. However, the staff role is inherently challenging in a clubhouse model as staff is required to encourage member participation despite numerous challenges, such as variances in members' psychiatric symptomatology and restraints related to job

responsibilities (simultaneously writing multiple grants etc.). Both clubhouses would serve lunch around noon. Members and staff in the culinary unit would work together to cook and distribute meals to other members and staff. Clubhouse Odyssey holds a house meeting, which usually lasts for around 10-15 minutes, every day after lunch. However, a house meeting is held once a week at Clubhouse Journey and lasts for around 60-90 minutes. House meetings are held to discuss any crucial updates or pressing issues. For instance, one of the house meetings I attended at Journey was held to discuss renovation plans for the clubhouse space. After house meetings, members and staff return to their tasks. Around 4:30 pm, staff close the premises at Odyssey, unless a member is waiting for a ride back home. Journey closes its premises around 5pm; however, its thrift shop is open until 6pm on weekdays.

Most members and staff had their usual routines that they generally followed. Staff worked in their assigned units, unless there was a staff shortage during which a staff personnel would help manage more than one unit. Similar to staff, members also participated regularly in their preferred unit. For example, during the study period, Nolan (member) came regularly to the clubhouse around 1pm and mostly helped staff in maintaining records in the administrative unit. Routines changed primarily when there was an unusual activity in the clubhouses, such as painting the walls of a unit or being visited by an accreditation agency.

Similar to members and staff, I also participated in the daily activities of the clubhouse. I engaged in occupations that ranged from cooking to providing assistance in grant writing. It is through participation in these occupations that I learned the complex nature of staff-member relationships and gained understanding of the implicit rules for participation at the clubhouses, including how those rules surfaced during everyday occupations.

3.6 Participants

For members, demographic data were collected either during the interviews via a demographic questionnaire or by accessing the mental healthcare records, after receiving participant consent. However, one member participant did not provide consent for accessing healthcare records, and thus, information related to that participant is unknown. Further, healthcare records did not always have the updated information about a few members so specific demographic information, such as current medication, for some members is unknown. Staff participants' demographic data were collected during the interview through the demographic questionnaire.

3.6.1 Member Participants

Members or adults with serious mental illness were recruited via purposive sampling (without stratification) as perspectives from consumers with specific characteristics were needed. The eligibility criteria included: 1) age more than 18 years; 2) diagnosis of a serious mental illness; and 3) ability to communicate in English. To avoid potential confounders of stigma, individuals who reported utilizing treatment for substance abuse and developmental disorders were not recruited. Eighteen members participated in the study (n=9 from each clubhouse). Informed consent was obtained from each participant (Appendix A). All but one member participant provided consent for release of medical information (Appendix B); thus, clinical data and clubhouse notes of one participant were not included in the analysis. The mean age for members was 49.23 years (SD=12.91) and ranged from 30 to 67 years (Table 2). The mean number of years for clubhouse membership was 15 years and ranged from 1 year to 28 years. Gender was equally distributed with nine male and nine female members. All member participants had a primary diagnosis of schizophrenia. All but one participant were single or

divorced. All but three participants were taking some kind of psychiatric medication. Twelve participants identified as Caucasian and six as African-American or black. During the study period, most member-participants engaged almost daily at their respective clubhouses and others participated around 2 days/week.

Regarding demographic differences between the clubhouses, a majority of the participants from Odyssey identified as African-American (n=5, 55.5%); however, a majority of the participants from Journey identified as Caucasians (n=8, 88.8%) and only one identified as African-American. Further, a majority of the participants from Odyssey identified as female (n=6, 66.6%); however, a majority of the participants from Journey identified as male (n=7, 77.7%). Participants also differed on the basis of housing situation as a majority of the participants in Journey reported living in a rented apartment (n=7, 77.7%) while a majority of the participants in Odyssey reported living in a group home (n=4, 44.4%). Participants from Journey also reported having more education as a majority of the participants reported gaining some college experience or having a college degree (n=6, 66.6%) while no participant from Odyssey reported gaining any college experience. The samples did not differ on other demographic indicators.

3.6.2 Staff Participants

Staff (n=16) were recruited via convenience sampling, as comprehensive perspectives regarding the research questions were needed and perspectives of service-providers with specific characteristics (known as purposive sampling) or based on specific theoretical ideas (known as theoretical sampling) were not sought. The eligibility criteria included: 1) age more than 18 years; 2) ability to communicate in English; and 3) currently providing services at a clubhouse. Sixteen staff participated in the study. Most participants (n=13) identified as female, with 3

participants identifying as male. Most staff participants (n=12) identified as Caucasians while three participants identified as African-American and one as Iranian-American. On average, the staff had been working in their respective clubhouse for around 5 years. Educationally, while few staff (n=5) reported having an undergraduate degree, most staff personnel had graduate degrees in social work or other healthcare related fields.

Table 2. Member participant demographics

Demographics	Services-users or members (n=18)
Age	49.23±12.91 years
Gender	Female=50% (n=9)
Race	White=66.6% (n=12) Black=33.3% (n=6)
Primary Diagnosis	Schizophrenia=100% (n=18)
Education	College=16.6% (n=3) Associates Degree=5.5% (n=1) Some College=27.7% (n=5) High School=22.2% (n=4) Some High School=16.6% (n=3) Unknown=11.1% (n=2)
Employment	Employed=16.6% (n=3) Transitional employment =5.5% (n=1) Self-Employed=5.5% (n=1) Unemployed=66.6% (n=12) Unknown=5.5% (n=1)
Housing	Rented apartment=50% (n=9) Group home=22.2% (n=4) With Family=22.2% (n=4) Unknown=5.5% (n=1)
Marital Status	Married=5.5% (n=1) Separated or Divorced=22.2% (n=4) Single or unmarried=55.5% (n=10) Unknown=16.6% (n=3)
Past Incarceration	Yes=5.5% (n=1) No=88.88% (n=16) Unknown=5.5% (n=1)
Currently taking psychiatric medicine	Yes=66.6% (n=12) No=16.6% (n=3) Unknown=16.6% (n=3)

3.6.3 Policy Experts

Policy experts were recruited via convenient and snowball sampling strategies. For instance, a policy expert was recruited after a member introduced us during a fieldwork day and another was recruited based on a policy expert's suggestion. I interviewed seven policy experts for this study. Experts interviewed for the study included a state legislator, a former director of a county mental healthcare system, two mental health law experts, a clubhouse board member, a mental health consumer engaged in policy, and an official examining the state's mental healthcare system. I have not included demographic characteristics for policy experts since the information is not essential and presenting that information could compromise confidentiality.

3.7 Methods

Ethnographic methods involve extensive contact with participants, immersion in the context where the phenomenon of interest is manifest, and recording perspectives from participants (Snow et al, 2003; Willis & Trondman, 2000). Methods employed for this study were semi-structured interviews, participant observations, and document reviews (Table 3). In addition, I used the Community Participation Measure to collect data on the community participation of clubhouse members (Salzer, Brusilovskiy, Pruv-Bettger, & Kottsieper, 2014).

3.7.1 Semi-structured Interviews

Interviews, as a distinct method, first surfaced in social science research through survey methodology, where interviewees were asked to respond to questions by either choosing an option from a set of responses or providing their views on the questions posed (Fontana & Frey, 2000). However, departing from the question-response conceptualization, interviews are now considered as co-constructed and negotiated textual discourses between interviewers and interviewees (Fontana & Frey, 2000). Interviews are particularly helpful in eliciting participants'

reflections on past experiences, opinions, and emotions about a topic of interest while providing a researcher the ability to ask queries related to a research question (Mack, Woodsong, MacQueen, Guest, & Namey, 2005).

Semi-structured interviews allowed me to ask participants questions that were directly related to my research aims while providing participants the opportunity to expand on issues they wished to communicate. Semi-structured interviews also allowed me to add additional questions based on an interviewee's responses, a technique called probing (Bernard, 2006).

Table 3. Overview of methods

Methods		Participants included	Activities/Context Included	Specific aim addressed
Participant interviews	Semi-structured Interviews	M + S	Scheduled interviews at a participant's preferred location or clubhouse	1,2,3
	Semi-Structured Interviews	PE	Participant's preferred location	3
	Survey Measurement	M	At the end of interview	2
Fieldwork and participant observation	Field notes	M + S	Observations of and participation in activities with recruited participants at the clubhouse and in community	1,2,3
Document Review	Document Review	None	Review of documents related to mental healthcare planning and implementation at the clubhouse	3

M=Members; S= Staff; PE=Policy experts

I interviewed clubhouse members to gather their perspectives on stigma and occupational engagement (mental healthcare and community). I also conducted interviews with staff at the two clubhouses. Interview responses from staff helped elicit their perspectives on stigma, occupational engagement in the clubhouse model and factors influencing occupational

engagement of the members (such as mental healthcare policies). I also conducted interviews with mental healthcare policy experts to gather their perspectives on stigma and mental healthcare policies.

I used an interview guide (Appendix C) to conduct the interviews. Interviews were audio-recorded with permission from the interviewees and were conducted at a clubhouse, local public library or at a site preferred by a participant. Interviews lasted an hour on average (range=35-113 minutes). I transcribed all the interviews verbatim.

Community participation measure. I used the Community Participation Measure (Salzer et al., 2014) to measure community participation among the members. The purpose of this measure is to assess the community participation of adults with serious mental illness outside the context of healthcare. The scale has acceptable reliability and has been validated (Salzer et al., 2014). The measure was administered after each interview with a member. This measure also served as a probe to generate additional questions about community participation during an interview. For example, while the measure does not ask questions regarding factors influencing one's community participation, I enquired about factors influencing specific aspects of community participation, such as advocacy, to gain additional information.

3.7.2 Fieldwork and Participant Observation

Fieldwork can be described as an inter-subjective, historical, and political discourse in which researchers and participants take part (Adler & Adler, 1987; Clifford, 1990; Snow et al., 2003). During fieldwork a researcher participates with research participants in their typical activities of daily life. In this case, fieldwork occurred at the two clubhouses and in nearby communities. While interviews have limited occurrences, fieldwork allowed me to participate and explore issues of interest over an extended time period.

Fieldwork allowed me to observe participants' experiences at the clubhouses firsthand. I engaged in social activities with study participants (members and staff) to explore my research questions. I participated in the daily routines of the clubhouses and in various special events. For example, two of my fieldwork observations included participation in a clubhouse social at a bowling alley and a policy-focused meeting with local county commissioners that I attended with members and staff. My fieldwork typically included working on various tasks with staff and members, such as helping to cook a meal, writing grants, and guiding unit meetings with a member. My participation also included a significant portion of "hanging out" with members and staff such as talking with members in the smoking area, going out for lunch with members, or talking with staff while driving to a meeting. Participation in such activities helped me to contextualize the occupational engagement of participants by being in the context. Unlike interviews, this allowed me to construct explanatory arguments regarding some of the findings that are discussed later.

In addition, I also engaged in opportunistic interviews during participant observations in the community and at the clubhouses. Such interviews helped me explore immediate or current events, which I deemed important for the research investigation. These interviews were usually not audio-recorded, so I recorded my observations in fieldnotes. There were a few instances when an opportunistic interview was audio-recorded, after obtaining participant consent. For instance: one interview was conducted with a member to gather his perspectives on a recent clubhouse tour.

I participated in fieldwork for 4-5 days/week (2-3 days/week at each clubhouse) for around 6 hours/day, for 6 months (more than 600 hours). I used an observation guide (Appendix D) to document my observations during the fieldwork in field notes, which were written within

24-48 hours after the end of every visit. In addition to my observations, I also documented my thoughts and reflections in the field notes. In order to bypass the limitation of memory, I also took brief notes during fieldwork observations. Writing field notes also generated questions that I subsequently asked during interviews. Since field notes are inevitably biased towards research questions and researcher interests, the field notes I generated for this study were focused on aspects related to the primary research objective and specific aims (Clifford, 1990).

3.7.3 Document Reviews

Document review is a systematic procedure to analyze documents that are pertinent to a research question (Bowen, 2009). After obtaining consent from members, I accessed members' mental healthcare records and clubhouse intervention notes, such as weekly notes that document members' weekly psychosocial progress. I collected this data to understand the tools, including policies, that shape member and staff interactions and relationships. The documents also helped me understand the context of the mental healthcare system in the state. For example, Nolan (member, pseudonym) was confused and frustrated when he found out that he could not access his own psychiatric care plan unless he had authorization from his service-provider. Nolan questioned the basis of such policies/strategies and shared that such practices allow stigma to function on a larger level as consumers are not considered fit to access even their own psychiatric records.

My review of documents consisted of examining and interpreting documents. I noted my observations and evaluation of documents in my field notes. Methodologically, these documents and their evaluation helped me triangulate data, when coupled with interview and fieldwork data, to better understand the social processes related to stigma and occupational engagement (Denzin,

1978). Thus, this practice helped me to increase the trustworthiness of my findings (Bowen, 2009).

3.8 Data Analysis

Data collection and analysis are overlapping processes in a qualitative inquiry (Sandelowski, 1995). During data collection, a researcher is simultaneously immersed in exploring and understanding a phenomenon, which subsequently influences future observations, interview probes, and data analyses (Becker, 1998). Repeated iterations of data collection and analysis in qualitative enquiry help a researcher untangle the complexity of a phenomenon. I engaged in such an iterative process of data collection and analysis. For example, analysis of state policy documents during the early phases of the study helped generate questions for policy experts' interviews conducted later in the study. Further, transcribing interviews during data collection aided in preliminary data analysis, which helped inform subsequent interviews.

I began data analysis using open coding. Open coding is a process of giving a label to a portion of data (interview transcripts and field notes) that a researcher deems as a set of ideas requiring attention. Open coding also allows recognizing similarities or differences within a data set, during early phases of analysis (Corbin & Strauss, 2008; Saldaña, 2013). Generating field notes and transcribing interviews provided me an opportunity to continually assess and learn participants' perspectives. I also randomly selected and read a few field notes and interview transcripts to get a preliminary idea of the data collected. Due to the specificity of my research questions and aims, I began open coding with a few preliminary codes or larger categories, such as "perspectives on stigma" and "clubhouse participation." During the process of open coding, I consolidated the data into the categories that were either generated for their relevance to the research questions or identified during the preliminary read of the data. I conducted two rounds

of open coding, which led to the generation of 4 primary codes and 17 secondary codes (Appendix E).

After employing open coding, I used focused coding to bring together identified groupings of codes based on the relationships between them (Corbin & Strauss, 2008; Starks & Trinidad, 2007; Saldaña, 2015). Thus, focused coding involved identifying patterns or processes among the coded sets, using a second level of inductive analysis. For example, focused coding allowed connecting challenges experienced by staff to engage members with economic struggles to maintain a clubhouse, which are, partly, due to lack of effective mental healthcare policies.

Open and focused coding primarily entailed a descriptive strategy to analyze data. During coding, I did not provide explanations regarding why or how the phenomenon presented itself in the way it did. Therefore, in accordance with the primary purpose of exploring the social processes guiding experiences of stigma and occupational engagement, I interpreted the collected data. Qualitative data interpretation is the process during which a researcher provides his or her understanding or account of the data and potential explanations regarding the phenomenon being studied (Peshkin, 2000).

Thus, my third level of analysis involved interpreting data in a manner that helped answer the research questions while remaining faithful to participants' voices. For example, participants provided various perspectives on what stigma can be during an interview; however, I do not present a model of stigma that is based on frequency or quantitative analysis of perspectives presented. I imbued participants' perspectives with my understanding of their occupational engagement (via fieldwork observation) and contemporary evidence regarding stigma. Thus, the findings may not include all the numerous perspectives on stigma, as they are a distillation of data collected for this study, using a sieve of my understanding of participants' views and

existing knowledge. This interpretive approach to data analysis led to the generation of models, concepts, and principles that I present in the following chapters.

Finally, the Community Participation Measure (Salzer et al., 2014) scores were analyzed using descriptive statistics (e.g., frequencies and item means). However, statistical findings from the measurement are not reported, as a small sample size limits reporting statistically significant findings and no statistical strategy was employed to account for the small sample size.

3.9 Conclusion

This chapter described the methodology and the methods employed to collect and analyze data for this study. This chapter also provided details regarding the research sites and the participants recruited for the study. I also elaborated on my role and biases as a student researcher, a key aspect when conducting an ethnography. The following three chapters describe key findings of the data analysis, in the form of three distinct papers.

CHAPTER 4: UNDERSTANDING THE MORAL ECONOMICS OF OCCUPATIONAL ENGAGEMENT

4.1 Introduction

A significant portion of occupational science scholarship aims to understand why humans do what they do and how occupations are related to health (Clark et al., 1991; Hocking, 2009; Yerxa, 1993). Occupational science scholars agree that humans are occupational beings and that occupations are integral to sustain life as a human (Wilcock, 2006). However, assumptions related to conceptualizations of occupations continue to be challenged. For example, the concept of occupational imbalance proposes that an imbalance in one's daily routine is detrimental to human health; additionally, different types of occupations can be used to shift one's occupational balance towards desired health outcomes (Townsend & Wilcock, 2004). However, these assumptions have been challenged and occupational engagement is not conceptualized simply as participation in a structured routine revolving around normative expectations of healthy behavior (Anaby, Jarus, Backman, & Zumbo, 2010; Hammell, 2009; Hammell & Beagan, 2017). In order to better understand the relevance of occupations for human health, occupational science scholars must better understand the unit of occupation and the social processes that underlie occupational engagement⁸.

Occupations were initially conceptualized through an individualistic perspective; however, now there is a wide agreement that occupations are not entirely individualistic and are

⁸ Using Bourdieu's (1998) ideas of habitus and social field that undergird human actions, I conceptualize occupational engagement as participation in any social act.

inextricable from social context (Clark et al., 1991; Cutchin et al., 2008; Dickie, Cutchin, & Humphry, 2006; Morris & Cox, 2017; Royeen, 2002). Regarding social context, it is advocated that occupations exist within value⁹ systems that guide occupational engagement (Angell, 2012; Laliberte Rudman, 2012; Nyman, Josephsson, & Isaksson, 2014; Prodinger, Laliberte Rudman, & Shaw, 2015). However, given the complex nature of occupational engagement, occupations are rarely conceptualized as tangible assets existing within a value system, having socio-economic value. For example, the occupations that a “good” mother can or should do have been considered as non-economic responsibilities for women; however, the occupational engagement of a mother has a significant economic and social value (Christopher, 2012; Duncan & Edwards, 1997; Primeau, 2000; Waring, 2017). Thus, despite the abstract formulations of occupations, occupations do have tangible socio-economic values and are integral for positioning individuals in social spaces.

Regarding social space, occupational science scholars have highlighted the hierarchical and situated nature of occupational engagement (Angell, 2012; Galvaan, 2015; Laliberte Rudman & Huot, 2013; Madsen & Josephson, 2017; Prodinger et al., 2015). Occupations have been conceptualized as sites for conscious or unconscious enactment of power that maintain social hierarchies within a social space or arena (Angell, 2012). The unconscious nature of occupational engagement also aids in implicit negotiations of power that sustain the hierarchical nature of occupations (Angell, 2012; Cutchin et al., 2008; Prodinger et al., 2015). However, despite such active acknowledgement of the hierarchical and situated nature of occupations, there is a paucity of research exploring the social processes that explain the situatedness of

⁹ Value here refers to capital based on skills and/or socio-economic assets.

occupations and their role in maintaining social hierarchies (Hocking & Whiteford, 2012; Proding et al., 2015).

One of the goals for studying the situatedness of occupational engagement is to better address concerns of occupational justice (Bailliard, 2016; Hammell & Beagan, 2017; Laliberte Rudman & Forwell, 2013). Scholars have highlighted the influence of various contextual factors, such as governmental practices, on maintaining injustices related to occupational engagement by constraining opportunities for participation (Johnson & Bagatell, 2017; Laliberte Rudman, 2012). However, the current literature provides little understanding regarding the social processes that allow occupational injustices to exist as normative practices (Hammell & Beagan, 2017; Hocking & Whiteford, 2012). It is unlikely that the occupational injustices experienced by marginalized populations can be effectively addressed if occupational scientists do not adequately unveil the social processes that maintain occupational engagement as sites for both sustaining and dismantling social discrimination and marginalization (Angell, 2012; Bailliard, 2016; Hammell & Beagan, 2017). To address the lack of evidence regarding social processes related to occupational engagement, a primary aim of this study was to understand the social processes guiding occupational engagement.

4.2 Methods

4.2.1 Data Collection Sites

An ethnographic study was undertaken at two clubhouses, Journey and Odyssey (both pseudonyms), in a southeastern state in the United States. The clubhouse model is a psychosocial rehabilitation model organized to support adults with serious mental illness (SMI). Clubhouses are non-profit settings and receive financial support or reimbursement for services via federal programs (such as Medicaid), local/foundation grants, and donations. In the clubhouse model,

adults with SMI are referred to as members. Membership in a clubhouse is voluntary and members “have equal access to every Clubhouse opportunity with no differentiation based on diagnosis or level of functioning” (Clubhouse International, 2016, p. 1). A clubhouse is comprised of various units such as the membership, administrative, and transitional employment units. Members and staff work together in tasks, such as cooking and writing grants, to sustain their clubhouse. During the study period, Clubhouse Journey and Clubhouse Odyssey had an active membership of 104 and 88 members, and on average 32 and 19 members participated there on a daily basis, respectively.

The study was approved by the Institutional Review Board at University of North Carolina-Chapel Hill.

4.2.2 Participants

Participants included clubhouse members (n=18) and staff (n=16).

Members. Members were recruited via purposive sampling. Inclusion criteria were: 1) age more than 18 years; 2) a diagnosis of a serious mental illness, which was confirmed via medical records; and 3) ability to communicate in English. To avoid potential confounders of stigma, adults receiving treatment for concurrent substance abuse and developmental disorders were not recruited. Eighteen members participated in the study (n=9 from each clubhouse). Informed consent was obtained from each participant. All but one participant provided consent for release of medical information (Appendix B). The mean age for members was 49.23 years (SD=12.91) (Table – 1). Gender was equally distributed, and every participant had a primary diagnosis of schizophrenia or schizoaffective disorder. Twelve participants were taking medication for their psychiatric condition. Twelve participants identified as Caucasian or white and the rest as African-American or black.

Table 4. Member participant demographics

Demographics	Services-users or members (n=18)
Age	49.23±12.91 years
Gender	Female=50% (n=9)
Race	White=66.6% (n=12) Black=33.3% (n=6)
Primary Diagnosis	Schizophrenia=100% (n=18)
Education	College=16.6% (n=3) Associates Degree=5.5% (n=1) Some College=27.7% (n=5) High School=22.2% (n=4) Some High School=16.6% (n=3) Unknown=11.1% (n=2)
Employment	Employed=16.6% (n=3) Transitional employment =5.5% (n=1) Self-Employed=5.5% (n=1) Unemployed=66.6% (n=12) Unknown=5.5% (n=1)
Housing	Rented apartment=50% (n=9) Group home=22.2% (n=4) With Family=22.2% (n=4) Unknown=5.5% (n=1)
Marital Status	Married=5.5% (n=1) Separated or Divorced=22.2% (n=4) Single or unmarried=55.5% (n=10) Unknown=16.6% (n=3)
Past Incarceration	Yes=5.5% (n=1) No=88.88% (n=16) Unknown=5.5% (n=1)
Currently taking psychiatric medicine	Yes=66.6% (n=12) No=16.6% (n=3) Unknown=16.6% (n=3)

Staff participants. Staff or service-providers (n=16) were recruited via convenience sampling. The inclusion criteria were: 1) age more than 18 years; 2) ability to communicate in English; and 3) currently providing services at a clubhouse. Thirteen participants identified as female and three participants identified as male. Most participants (n=12) identified as Caucasians while three participants identified as African-American and one as Iranian-American. On average, staff have been working at the clubhouses for around 5 years.

4.2.3 Data Collection Methods

The data were collected over a period of six months via interviews, fieldwork/participant observations, and document review of participant members' mental healthcare records and relevant local/state policy documents.

Interviews. I conducted semi-structured interviews, using an interview guide (Appendix C) to gather participants' perspectives on stigma, occupational engagement (mental healthcare and in community), and mental healthcare policy. Interviews were audio-recorded (with permission) and lasted an hour on average (range=35-113minutes). All interviews were transcribed verbatim.

Fieldwork. I conducted fieldwork/participant observations at the clubhouses and in the nearby communities for 6 months. I participated in typical activities in the clubhouse (5-6 hours/day for 4-5 days/week for 6 months) and attended community outings sponsored by the clubhouses (e.g., bowling). Field notes were created for each field visit.

Document review. I reviewed members' mental healthcare records, clubhouse intervention notes, and local/state policy documents. The review consisted of reading, evaluation, and interpretation of the documents (Bowen, 2009).

4.3 Analysis

I analyzed data using open and focused coding. Open coding is a process of giving a label to a portion of data (interview transcripts or field notes) that a researcher deems as a set of ideas requiring attention (Corbin & Strauss, 2008; Saldaña, 2015). During this process, I consolidated the data into categories (sets) that were relevant for the research purpose such as "member engagement" and "staff/member interactions." Next, I used focused coding to identify patterns among the identified coded sets (Corbin & Strauss, 2008; Saldaña, 2015). My third level of

analysis focused on interpreting data in a manner that helped identify social processes while remaining faithful to the participants' voices (Snow, Morrill, & Anderson, 2003). For example, textual data, such as weekly intervention notes documenting member participation, were interpreted to understand their role in maintaining institutional practices via occupational engagement. This interpretive approach to data analysis led to the generation of the framework presented here (Figure 1).

4.4 Results

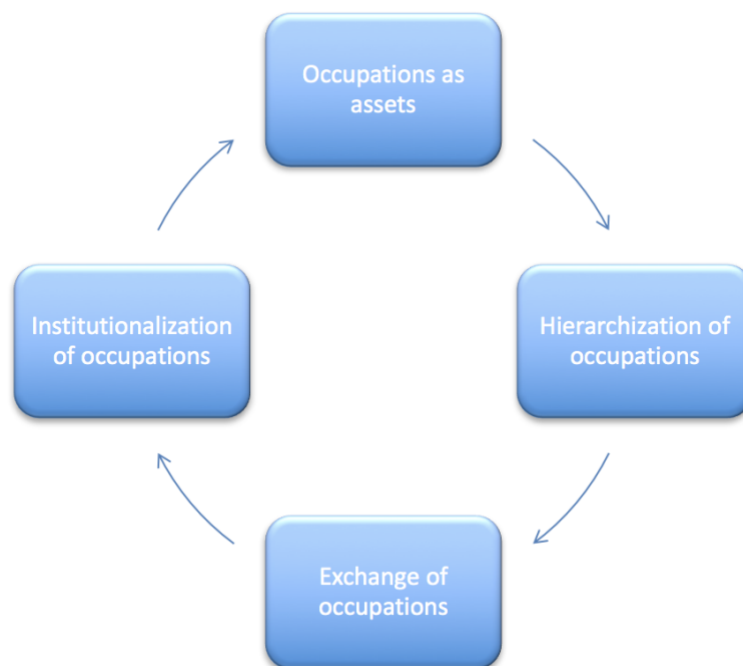


Figure 1. Framework conceptualizing the moral economics of occupational engagement.

4.4.1 Occupations as Assets

During fieldwork and participant interviews, it was evident that occupations were not simply acts that were carried out in a way that no consequence or outcome was desired. If members and staff were cooking, then a desired consequence or outcome was to have a certain amount of cooked food for the members. Thus, the desired consequence dictated the occupational engagement itself. Being able to cook food in a timely manner requires a certain set

of skills and motivation from both members and staff. These criteria established prerequisites to participate in the occupation of cooking at the clubhouse. Being able to participate in the kitchen allowed certain members to spend their time meaningfully in the clubhouse and provided the opportunity to gain or maintain various skills, which could be used for employment purposes. For instance, since cooking was a meaningful occupation for Eduardo (member), he helped in the kitchen on a regular basis. At multiple times during the fieldwork, he also asked me about recipes for various Indian dishes, and it was not unusual to see him with a recipe book. Due to his interest and participation in the culinary unit, he also represented the unit on numerous clubhouse tours at Journey. The skills he gained also helped him in gaining a transitional employment opportunity. Thus, the occupation of cooking clearly proved to be an asset for Eduardo. For staff, participating in the kitchen meant being able to spend some of their working hours for the purposes of remuneration. Time spent by members in cooking can be billed as psychosocial rehabilitation and is monetarily reimbursed to the clubhouse. Economic resources are also spent as food and other amenities (such as electricity) are utilized for cooking. Thus, participating in the occupation of cooking food is an asset since skills or economic capital are gained or spent. Adding to this aspect, Eugene (member) reported that the economic value of his occupational engagement superseded the other incentives to participate:

It's just no longer rewarding for me (to participate in clubhouse regularly) to give all my time without remuneration. I've gotten to a point in my life where if I'm going to contribute (participate) there I want to have something coming back.

Eugene conceptualized his occupational engagement in terms of an asset or contribution requiring economical exchange via remuneration. Jocelyn (member) shared similar sentiments:

I sign in and sign out so I know... the paying rate is like 20 an hour (actual reimbursement rate is around \$4 per 15 minutes) that they got for me... they're getting paid because I sign my name...

Jocelyn was more explicit in her views while highlighting her occupational engagement as economical, as she illustrated that a clubhouse gets money for every minute a member participates in a clubhouse. Further, during the study period, Julio, a member who participated frequently at Clubhouse Journey got a transitional employment opportunity to work in a hotel. It was clear that his job at the hotel included skills similar to the tasks that he did in the clubhouse (such as cleaning). Thus, skills acquired via occupational engagement at the clubhouse were converted into employment skills that were economically reimbursed via occupational engagement at the hotel, highlighting the economic significance of occupational engagement.

Besides equating occupations to economic assets, participants also highlighted occupations as symbolic or cultural assets. Ryan (service provider) shared:

If you're engaging members more and more than they're going to have authority and then they have ownership (of the clubhouse).

Thus, occupational engagement corresponded with a member's sense of ownership of a clubhouse, an aspect that was strengthened via fieldwork. For example, members who participated more than other members took leadership roles in clubhouse tours and other social activities in the clubhouse. Such immersive participation provided certain members skills and opportunities to further participate in advocacy efforts within a community and gain social capital among peers and others, as Johnny (member) shared:

My sister got me more involved in advocacy especially after I got to the clubhouse... and the director of our clubhouse at the time... asked me to come with her to an interview for a radio show... a really popular rock music station. So, I interviewed in that radio show. It was half an hour radio show and that's kind of where I got started in advocacy and doing that kind of public speaking.

Participation in occupations within clubhouses led to the accumulation or loss of socio-economic capital. Therefore, occupations can be conceptualized as tangible assets.

4.4.2 Hierarchization of Occupations

Conceptualizing occupations as assets suggests a hierarchization of occupations.

Anything or any social act that has a value exists in relation with other things or acts that have more or less value, and thus, exists in an order or a hierarchy (Bourdieu, 1998). Indeed, during fieldwork at Clubhouse Journey, a member expressed his dilemma on work for the day.

I mean I can work on some organizing (in the thrift store) but Rachel's (staff) order is that we will be reorganizing stuff after two days so I don't think I should do anything here.

The quote above highlights that hierarchy in occupations (who has the agency to do what) is maintained by social actors. For example, staff mostly guided or mentored members in the occupation of cooking. Further, social actors are not always aware of all the power dynamics functioning in a context (Bourdieu, 1998). Even in institutions whose existence depends on hierarchies (unlike clubhouses), social actors cannot always comprehend the extent of all power dynamics that operate on a daily basis. Regarding the implicit nature of power dynamics, Whitney (staff) shared her experience:

When I first came here, it was just the layers of sort of power dynamics, I guess. It plays every moment of the day and most of the time we're just moving through them and we're not really consciously evaluating them.

Here, power dynamics or hierarchy do not necessarily have a negative connotation, as a tool to seek absolute subjugation. For example, a parent can employ his/her authority/power or hierarchical position over a child in order to protect him/her from a potential harm. Power is conceptualized here as a tool to select who gets to do what kind of occupations (Nyman et al., 2014). In the context of the clubhouse, John (member) shared views regarding the necessity and positive impact of hierarchy:

So, the hierarchy is intentional because there is material to be taught and I think the main way of describing that material would be for the person (member) to find his or her way

so they would be able to lead a life in society and one of the ways for that is to be able to work on the appearance. Another one is to develop skills so that they (members) will be able to know how to start to find a job and start somewhere.

John highlighted that hierarchy in occupational engagement at clubhouses exist to provide members opportunities to develop skills, such as vocational skills, that can assist in community participation. For instance, while there is no explicit hierarchy in a clubhouse model, most tasks, such as cooking, cleaning, arranging clothes in a thrift store, are guided or led by a staff. During a fieldwork day, I participated with members in arranging clothes in Clubhouse Journey's thrift store. Throughout the task, Rachel, as per staff responsibilities, supervised members' and my work to make sure that we were doing the task as she wished it to be done. Throughout the task her managerial superiority and hierarchical position over members and myself (as a staff) was evident. For example, she insisted on making sure that we placed clothes on the hangers in a specific direction. However, her guidance was not an explicit desire to demonstrate her managerial superiority as a staff but to ensure that the customers could take off clothes from the hangers easily. The task was beneficial for members and myself as we learned the operations of the thrift store so that we could manage it when Rachel is not present. Thus, the implicit hierarchy did provide members a chance to gain skills that can assist them in acquiring employment opportunities.

A person's positionality within a clubhouse social space granted or prevented access to different tasks within the occupational hierarchy. For instance, Jerry (staff) explained how some occupations were "untouchable" and only accessible to those in higher positions: "the untouchable tasks ... are the tasks that members feel as though that they can't do without the staff there... (like) the email, like that's for the higher up people." Thus, untouchable tasks are sets of occupations that are available mostly to the staff as they have more agency. It is important to

note here that hierarchy is not an explicit desire of a clubhouse staff but, partly, a consequence of institutional factors that govern and sustain hierarchies.

The hierarchy of occupational engagement also existed between the clubhouse members. Members who participated in occupations related to leadership roles were perceived to occupy a higher position than other members, as Johnny (member) shared:

There's hierarchy in clubhouses, not so much between member and staff but really between member and member because there are a lot of members in leadership roles such as myself... that (leadership roles) places us above, sort of a hierarchical level, the other members. So a lot of members were pointing out that "hey there really is a hierarchical relationship." We (clubhouses) admit that now and we try to deal with that in an honest manner.

Stella (member) also characterized an implicit hierarchy among members based on their perceived efficiency in occupational engagement

I think that, as a member, I know there's some people here that are just able to get up, get dressed, come here and have a place to come to, and then there are those people... who work in their own recovery and are very good at doing jobs here, very good leadership roles and then they're just people in the middle of those.

Further, while hierarchy may exist between members, no explicit competition among members for moving up in a hierarchy, via accumulation or confiscation of social capital, was observed or conveyed.

Finally, hierarchy is not necessarily a social condition of social actors; occupations exist in hierarchical relationships. Within the clubhouses, social actors changed frequently; however, the occupations associated with their positions did not. In both the clubhouses, at least one staff person left his/her position before the study was over and a new staff person took over. However, the occupations associated with those positions (e.g., culinary unit leader, associate director) did not significantly change. Occupations help maintain social hierarchies within clubhouses and

those hierarchies are reinforced by the occupational engagement of social actors within the clubhouses.

4.4.3 Exchange of Occupations

In addition to having a hierarchy based on value, occupations can also be exchanged so that social actors can move within a social field or an institution. Thus, an individual can exchange one form of occupation with another for social or economic gains. Jocelyn shared an example of such an exchange:

The paying rate is like 20 an hour that they get for me. But they're getting paid because I sign my name there... I take advantage of them too. I use their copy machines (to print flyers for her business)... I get as many color copies as I can for free. I charge my e-cigarette there sometimes...

Designing and printing flyers were not menial tasks but meaningful occupations for Jocelyn as they were used to boost her business, an integral aspect of her daily occupational engagement.

In the context of the study, individual skills and motivation were determining factors for occupational engagement. Individuals who demonstrated desire and/or skills to engage in occupations were provided further opportunities to engage in more occupations. Due to policy- and economy-based barriers, staff decided which members to engage based on their skills, as Chloe (staff) stated, “you have to go by a member’s ability and what they are able to do and comprehend.” Thus, in a clubhouse, individual factors, such as desire and skills, along with systemic factors, such as policies and economy, dictated exchanges of occupations. However, study participants (both staff and members) believed that perceived abilities are not the best measure to engage members in occupations. It was partly due to policy or economic factors that staff recruited members who were perceived capable of performing certain tasks. Ryan (staff) illustrated:

With old members who have been around for a while, staff know that person, they know their limits and their challenges, but at the same time that doesn't mean we should let that stop us. So do some staff think that members cannot do certain things because of that? yeah... but, as I've seen, members can surprise you... now she's (an old member who started participating after few years of being a member) somebody who we regularly call on to do data entry and to take on important roles that can be challenging.

Further, in a clubhouse, members have the choice to participate or not to participate, and thus, have the agency to govern their occupational engagement with staff and to bar staff from an exchange of occupations. For instance, it was evident that John (member) liked to undertake tasks in the clubhouse as per his wishes. He would sometimes arrange furniture or do online research on mental healthcare policies. During a fieldwork day, John was helping in arranging and cleaning one of the clubhouses; however, he had a disagreement with Ryan (staff). After a discussion with Ryan, John decided to work by himself instead of utilizing assistance from Ryan. Thus, due to the agency provided in a clubhouse model to the members, John was able to bar staff in participating with him. The disagreements were later resolved and resulted in John and Ryan working alongside. Another example of exchanges based on members' choice were house meetings. Some members were aware of the value of their participation and they chose to go to the house meetings only when there was an item on the agenda that mattered to them. For instance, William (member) usually skipped unit meetings at Clubhouse Odyssey as he would use that time to take out trash bags in the clubhouse. William would usually join in the culinary or snack bar unit meetings when the weekly food menus were being decided. Further, it was not uncommon to see members exchange knowledge about engagement in various tasks (occupations) and guide newly hired staff in understanding the clubhouses' daily operations.

The exchange of occupations happens within complex socio-cultural and economic contexts. It was evident that the clubhouse model is based on exchanges of occupation, primarily

to assist adults with mental illness in gaining skills that help them (re)integrate into a community.

As John (member) explained:

The idea is of baseball. We have a bunch of pitchers (members) and you have the pitching coach (staff) and the idea for the pitching coach is to be able to get the most out of the pitchers...

The quote highlights that exchange of occupations to guide a member in gaining skills for successful community (re)integration is an integral aspect of the clubhouse model. Further, the exchanges are mutually beneficial as members also guide exchanges in occupations with staff to maintain the clubhouses. John (member) shared his perspective on members establishing rules (such as gaining trust) for exchanging occupations with new staff so that they know what to do in the future: “the staff member has to be able to gain the trust of people (members) who have the know-how and know what to do so they (staff) will eventually know what to do.” Thus, numerous exchanges of occupations occur on a daily basis to assist members in reaching their psychosocial rehabilitation goals. Finally, just like exchange of money helps sustain economic institutions, exchanges of occupations helps sustain socio-economic institutions.

4.4.4 Institutionalization via Engagement in Occupations and Tools of Occupations

Institutionalization via engagement in occupations. A purpose of assigning values to occupations and preserving them in a system of beliefs to maintain exchanges of occupation is to foster institutions as durable social systems. As highlighted above, occupational engagement in the clubhouses is the sole reason for its existence, as without member/staff participation, a clubhouse would not exist. Members had a sense of belonging in the clubhouse via occupational engagement, as Brody (member) shared:

I really felt like I was a part of the clubhouse when they asked me if I would mind putting the prepaid (food tickets) into the database every day... that's when I really felt like, okay, now I belong....

Further, occupational engagement was expressed as integral to the clubhouse model and its functioning. Members came to the clubhouses primarily to participate in occupations in a way that they desired, and when there was lack of participation members decreased their engagement in the clubhouses. Regarding the influence of lack of occupational engagement on being a member in the clubhouse, Nolan (member) shared:

I mean there should always be work (for members) at the clubhouse. How are you supposed to engage members? You know Nick (member) stopped coming to the clubhouse because he would come and ask staff here for work but they wouldn't have any so he just stopped coming.

Ryan (staff) also shared similar views regarding the importance of occupational engagement to sustain a clubhouse, as without members a clubhouse cannot exist:

When it (clubhouse occupations) does start to fall just on staff and staff start doing the majority of everything then members aren't here because they don't feel that they are needed...

As the quote above illustrates, members' occupational participation provided them a legitimacy of their role as a member, which helped sustain their everyday participation, and thus, a clubhouse. Jessie (staff) also shared similar sentiments and illustrated that an integral job function of a staff is to engage members in occupations at the clubhouse: "All staff should be engaging members because that's the most important aspect of the job."

Further, symbolic systems or institutions are economically maintained by conscious and unconscious efforts from social actors (Bourdieu, 1998; Bourdieu, 2000). There is a transfiguration or transformation of symbolic acts into economic acts and vice-versa (Bourdieu, 1998). Importantly, occupations are the units and sites for such transfiguration. The following fieldwork interaction highlights that while staff were compensated for their time at the clubhouse, they did not view their job as solely for monetary compensation.

Julio (member): You (Chloe, staff) are here because of the money.

Chloe: Let me tell you, if this was about money we would have gone some other place soon.

Another member: Clubhouse is about community. We come here, we bond, and we become one community.

This interaction highlights the transfiguration of an occupation from an explicitly economic act to a partly symbolic act, to strengthen the sense of community within the clubhouse. This interaction also highlights that “silence about the truth of the exchange is shared silence” as both members and staff conceptualize their participation beyond monetary compensation, even though members’ participation provided money for staff participation (Bourdieu, 1998, p. 97). However, to reiterate, such shared silence and arrangements exists primarily due to the unconscious nature of occupational engagement and contextual (policy/economic) restraints (Angell, 2012; Cutchin et al., 2008). Thus, the social rules and system of beliefs that guide exchanges and engagement in occupations within an institution are not formed of immutable rules but are contextual and complex.

Institutionalization via tools of occupations. Tools, such as texts, governed occupations in a clubhouse and were integral to its sustenance. For example, intervention notes (person-centered plans) at the clubhouses included goals chosen by the members for their participation in the clubhouse. Occupations outlined in texts are integral for clubhouse sustenance and functioning as the staff and member participation revolves around psychosocial rehabilitation goals that are focused on occupational engagement, such as gaining employment or participating in the clubhouse. This then helps establish and sustain a system of exchanges in occupations. The notes were also used to bill for the services provided and to maintain staff accountability. When Violet visited her family out-of-state for a month, staff lamented both her social absence and economic loss, as Abigail (staff) shared:

I mean in long term the attendance has decreased but it's lower in the weekends than weekdays. It affects our billing too. Violet is gone for a month and she comes seven days a week so it will affect our billing.

Another kind of text that dictated clubhouse functioning were weekly notes. Staff created weekly notes to record members' participation at the clubhouse. Each staff had about 10 members on their case load. An example of a weekly note entry is provided below:

Nolan attended Clubhouse Journey's PSR program for four days this week. Nolan practiced his prevocational skills in the Membership and Administration units. He worked on proofing attendance, Health and Safety program tasks, promotional material, web page design and Clubhouse Journey logo.

It is evident that the text above is steeped with information regarding occupational engagement, and thus, occupation is the primary unit for maintaining a clubhouse. Texts also impacted membership engagement as staff were required to spend a lot of time writing notes - time they believed could be better spent on engaging members. Indeed, Emi (staff) stated:

Administrative functions have expanded, which takes staff away from the day-to-day engagement with the members. I do feel like... it's a red tape issue where you're spending more time documenting the service versus providing the service, so that's been probably the more difficult shift over time.

Further, the texts also had significant meaning for the members. During a fieldwork day, Nolan asked to see his psychiatric records but Jessie (staff) informed Nolan that he cannot access them without his mental healthcare provider's permission. Nolan was visibly upset about this. Nolan also informed Melinda (member) about this issue when she walked in the unit. "Did you know about this, Melinda?" asked Nolan. Melinda seemed to know about this issue. However, both Melinda and Nolan were baffled and exasperated regarding this issue. Melinda was noticeably upset and suggested that having such a system insinuates a lack of trust on individuals with serious mental illness. Nolan was also baffled that he needed permission from his provider to access his own historical/medical records. "This is not just. You should have access to your

own history,” said Nolan. This instance highlights the influence of texts on not just institutional operations but also texts’ influence on establishing a hierarchy between the providers and the consumers, and the relevance of such texts on members’ notions about the mental healthcare system.

Finally, a staff participant elaborated on the influence of these texts in not just maintaining a clubhouse but also the kind of care that is decided by larger institutions for adults with mental illness, as Sharon (staff) shared:

Let’ go back to the notes. This is the way the system has developed. It's largely a medically based model and that's how Medicaid is framed as medically necessary. When you start getting into it, I think that we fail to recognize that if somebody needs physical rehab I mean that clearly seems to be something that is supported and necessary. But psychiatric rehab is not so much. The type of work that is needed for someone with serious mental illness is very different than your physical rehab.

Sharon highlighted that psychosocial rehabilitation is sometimes not viewed as medically necessary by larger institutions, which affects billing rates. Clubhouse Journey has been in multiple discussions with policy stakeholders to increase its billing rate to a similar rate as Clubhouse Odyssey (around \$15/hour), which is in a different county. Further, the texts are submitted to higher institutions for reimbursement, such as managed care organizations, that may evaluate psychiatric recovery as similar to physical recovery. For example, staff always expressed concern that psychiatric recovery is not always evident in a week’s time and yet they have to submit progress notes on a weekly basis. Thus, documentation of occupational engagement via texts helps maintain not just the institution of a clubhouse but also the larger institutions that dictate a clubhouse’s functioning.

4.5 Discussion

This paper proposes the framework of moral economics of occupations (MEOC) as a social process that guides occupational engagement. The MEOC helps in maintaining the power

relationships, hierarchy in and of occupations, and sustains institutions within which occupations occur. The MEOC framework emphasizes the situated nature of occupations, where context and individuals collectively guide occupational engagement.¹⁰ For example, the occupations in this study were performed by the members and staff participants and situated within the clubhouse. The clubhouse itself is situated within psychosocial rehabilitation, which is then situated within the arena of mental healthcare and so on. Additionally, staff's daily struggles to engage members resulted from the complexity of mental healthcare policies (context) that dictate the daily occupations in the clubhouse. For example, it was evident that moving up the hierarchy of staff positions resulted in fewer opportunities to engage members due to administrative pressures (i.e., gathering economic resources to maintain the clubhouse's daily operations, engaging in advocacy work to change problematic policies).

The MEOC framework illustrates that occupations are sites for the enactment of power relationships and that a person's agency to engage in occupations is determined by one's social position and capital (Galvaan, 2015; Nyman et al., 2013). For example, a staff highlighted the existence of untouchable tasks (such as email or driving) that were only associated with staff positions, primarily due to various institutional factors. Thus, depending on one's social position, different subsets of occupations are available to individuals (Figure 2). At the clubhouses, staff (Group 1 in Figure 2) were perceived as having higher social capital, and consequently, had more agency to participate in almost any occupation at the clubhouse. Members (Group 2 in Figure 2), were perceived as having lower social capital and could not participate in

¹⁰ Moral economics of occupational engagement cannot be understood from the lens of individualistic perspective on occupations, as such perspective may 1) underestimate influence of context and history and/or 2) overestimate an individuals' capacity to understand all the rationalities that implicitly govern their actions.

‘untouchable’ occupations¹¹. In simpler terms, using Bourdieu’s (1998) ideas and the study findings, the MEOC framework suggests that individuals with higher social capital have more agency to participate in more occupations, as compared to individuals with lower social capital. Under the MEOC framework, occupations are a unit of analysis that are associated with a group’s or an individual’s level of agency and social capital.

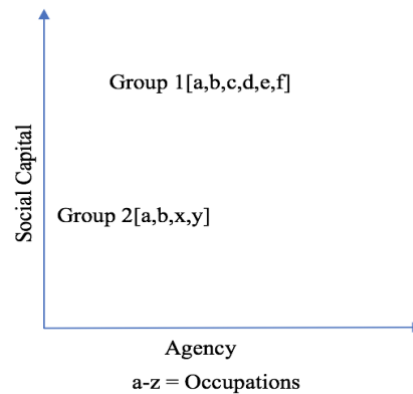


Figure 2. Relationship between social capital, agency, and occupations

The MEOC framework, primarily, discusses occupational engagement. However, the framework provides sufficient guidance to understand human beings as social actors engaging in systems of beliefs to participate in occupations (Bourdieu, 2000). Bourdieu (1998) proposed that habitus, acquired predispositions for human action, is informed by socio-economic dispositions towards a system of embodied beliefs. According to Bourdieu (1998), people participate in social activities in a way that there is an implicit agreement about the relative value of things and systems of behaviors. However, this agreement is not necessarily acknowledged via conscious calculations or decisions. People, both consciously and unconsciously, suppress the rules of participation to maintain a system of behaviors and beliefs. Bourdieu (1998) emphasized that self-deception is common among social actors who are mystifiers and mystified at the same time.

¹¹ Since occupations are situated, limitations put on a clubhouse by policy and social expectations contributed to disparity in occupational engagement at the clubhouses. However, despite limitations, staff tried as much as they could to engage members in various tasks.

Such mystification was evident in the clubhouse model. Participants described a tacit, but recognizable, hierarchy between and within staff and members, which was evident during occupational engagement. However, the clubhouse model eschews such hierarchy and thus, acknowledgement of these hierarchies are collectively repressed during daily occupational engagement. For example, while a thrift store or kitchen in a clubhouse should be operated jointly by members and staff, it was clear that many decisions were made by staff during usual operations. These hierarchies persist despite the best of intentions from staff and members, and due to economic and policy constraints that prevent the clubhouse model from reaching its full potential.

Discussion regarding the MEOC conceptual framework cannot be concluded without addressing the morality or the moral context under which occupations occur. Morals or morality are not an afterthought for this framework but the fabric that allows this framework to exist; however, obscurity and variations that underlie everyday morals or morality limit presenting conclusive findings about this aspect, at least in the context of this study. All human actions have some underlying moral rationality¹² though we may not be aware of it, but its obscurity does not negate its presence (Bourdieu, 1998; Foucault, 1969; Persson et al., 2001). However, due to the vague nature of or without a definition of morals or morality, the moral nature of occupations throughout the study was framed within value systems under which occupations took place. For example, members and staff at Clubhouse Journey smoked behind the clubhouse building to maintain a “decent” public image so that more community members would be willing to come on a tour and support the clubhouse. There is no set definition for the word “decent” that is

¹² Moral reasoning has been studied in the context of occupational therapy education (Brockett, 1996). Further, Dewey’s notions of human action, that continues to inform ideas related to human occupation, relies on moral imagination (Fesmire, 2003).

followed by members, staff and community members alike. However, smoking as an occupation was put under a value system where it was assumed or decided to be, by most members and staff, as an occupation that community members might not like to associate with a place like Clubhouse Journey. Under such moral context, members and staff engaged in the occupation of smoking. Further, the value of an occupation cannot be divorced from its moral nature. For example, there are moral rationalities that people employ to justify or condemn income inequality based on incentives for work (occupations), and those rationalities help maintain or challenge economic institutions (Sachweh, 2012). In the context of mental illness, it is due to stigma, which is framed under the moral lens of “irrational mind,” that adults with mental illness generally receive less opportunities to engage in formal employment, deteriorating their socio-economic position in a community (Corrigan, Larson, & Kuwabara, 2007; Pilgrim & Tomasini, 2012; Link & Phelan, 2014). Thus, as occupations exist under a veil of morality, their socio-economic value and exchanges occur under and maintain a system of beliefs, guiding the moral economics of occupations.

Finally, this study owes a significant debt to the clubhouse model. The clubhouse model relies on members’ occupational engagement and staff-member relationships to facilitate psychiatric recovery, providing the context and opportunity to study processes related to occupational engagement and its influence on the members. For instance, unlike various mental healthcare models, members at clubhouses have the agency to choose whichever staff they want to work with and what occupations they want to engage in, providing members the agency to shape their daily occupational engagement. By gathering perspectives from members about their occupational engagement and observing equitable member-staff relationships that undergird

daily occupations of the clubhouse model, the context of clubhouse allowed studying social processes related to occupational engagement.

4.6 Conclusion

Using findings from an ethnographic study, this paper proposes MEOC framework to illustrate a social process of occupational engagement. The framework highlights that occupations hold socio-economic value for individuals, and thus can be conceptualized as tangible assets. Conceptualizing occupations as assets allow occupations to sustain or challenge and become sites for enactment of social hierarchy or power relations, which could help either maintain or challenge an institution or institutional practices. Along with existing evidence, this study further bolsters the ideas that occupations are situated, hierarchical, and govern the sustenance of an institution, via its context and tools (Angell, 2012; Johnson, 2016; Laliberte Rudman, 2012; Prodinger et al., 2015). Merging findings of this study with Bourdieu's (1998) ideas on habitus and capital, it becomes clear that occupations are carried out amidst the ever-present force of history that guides a system of beliefs. Thus, all occupations are situated within some institution or culture¹³, where an exchange of knowledge or some sort of socio-economic capital is inevitable. Further, this study was conducted in an institutional setting, and thus, the findings may seem most appropriate for institutional settings. However, it is crucial to define and debate on what institutions are or how are they defined. Ideas from Bourdieu (1998, 2000) suggest that a home or a family unit is as much an institution as a clubhouse or a bank, as they all operate on the basis of some socio-economic and moral rules. Future research is required to evidence applicability and utility of this framework in non-traditional institutional settings, such as a family unit.

¹³ I use the terms institutions and cultures as codependent entities.

CHAPTER 5: CONCEPTUALIZING THE RELATIONSHIP BETWEEN STIGMA, POLICIES, AND COMMUNITY PARTICIPATION

By definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances. -E. Goffman (1963, p. 5)

5.1 Introduction

There is little doubt that humans are social beings and we maintain or improve our health and well-being via community participation¹⁴ (Axelrod, 1984; Haslam, Jetten, Postmes, & Haslam, 2009; Herrmann, Call, Hernández-Lloreda, Hare, & Tomasello, 2007; House, Landis, & Umberson, 1988; Uchino, Cacioppo, & Kiecolt-Glaser, 1996). However, community participation continues to be a concern for adults with serious mental illness (SMI). There are around 10.4 million adults living with SMI in the United States (U.S.) and many experience challenges related to community participation, such as homelessness, unemployment, and/or incarceration (Department of Housing and Urban Development [HUD], 2016; Luciano & Meara, 2014; Mechanic, Bilder, & McAlpine, 2002; SAMHSA, 2017; Torrey, Kennard, Eslinger, Lamb, & Pavle, 2010). Approximately, only 40% of adults with serious mental illness report being on full-time employment (Luciano & Meara, 2014; Mechanic et al., 2002). It is estimated that 36% (around 202,297) of people experiencing homelessness have a SMI (HUD, 2016; SAMHSA, 2017b). There are three times as many adults with SMI incarcerated in jails and prisons than in

¹⁴ Here, I conceptualize community participation as a domain of daily occupational engagement, as evidenced by Sakiyama and colleagues (2010), in the context of mental illness.

hospitals (Torrey et al., 2010). Community participation is indeed challenging if one does not have a home or resources to maintain one's self in a community, or is incarcerated and not in a community to begin with.

Lack of community participation adversely affects health and quality of life (QoL). Lack of adequate social relationships, support, and activities contributes to increased morbidity and mortality (Cacioppo & Cacioppo, 2014; Green et al., 2017; Liu et al., 2017). For example, living alone was found to be a significant predictor of mortality among adults with psychotic disorders (Keinänen et al., 2017). Lack of community participation also influences psychiatric recovery (Burns-Lynch, Brusilovskiy, & Salzer, 2016; Kaplan, Salzer, & Brusilovskiy, 2012; Yanos, Rose, Markus, & Lysaker, 2008). For instance: inadequate social relationships and lack of employment opportunities impedes psychiatric recovery (Eklund, Hansson, & Bejerholm, 2001; Kemmler, Holzner, Neudorfer, Meise, & Hinterhuber, 1997; Provencher, Gregg, Mead, & Mueser, 2002). However, it is important to note that community participation challenges are not solely related to psychiatric symptomatology.

Stigma, both on a personal/interactional and structural/institutional level, challenges community participation among adults with SMI (Link & Phelan, 2014; Thornicroft et al., 2009). For example, stigmatizing attitudes among employers contribute to low employment rates among adults with SMI (Baldwin & Marcus, 2011; Corrigan, Larson, Kuwabara, 2007; Stuart, 2006). Scholars argue that the transinstitutionalization of adults with SMI from the mental healthcare system to the criminal justice system is also, in part, due to the public's desire to keep this population away from their communities (for e.g., Torrey, 1998; Primeau, Bowers, Harrison, & XuXu, 2013). While there is no absolute consensus on a theory or definition of stigma or structural stigma, scholars agree that a feedback loop between stigma at the individual level and

at the structural level exists, allowing stigma to function across places and time (Pescosolido & Martin, 2015).

Various scholars have provided theoretical or conceptual frameworks connecting structural- and individual-level stigma (e.g., Pescosolido, Martin, Lang, & Olafsdottir, 2008; Yang et al., 2014). However, very few studies exist that focus explicitly on the influence of stigma on mental healthcare policies, which ultimately helps sustain structural stigma and challenges community participation among adults with SMI (Corrigan, Markowitz, & Watson, 2004; Pugh, Hatzenbuehler & Link, 2014; Thornicroft, Rose, Kassam, & Sartorius, 2007). One of the few studies existing within this realm evaluated legislative bills and found that multiple legislative bills restricted liberties (such as rights related to refusing treatment) of adults with SMI (Corrigan et al., 2005). Scholars have also highlighted policy-based restrictions on liberties for adults with mental illness (such as the right to vote and jury service) in other countries (Callard et al., 2012). For example, in the Netherlands, adults with mental illness were not able to exercise their right to vote until 2008 (Callard et al., 2012).

There are multiple reasons for the scarcity of specific policy analyses in mental health stigma research. First of all, there is a lack of consensus on outcomes that need to be operationalized or measured to specifically assess the influence of structural stigma (Estroff, Penn, & Toporek, 2004; Pescosolido & Martin, 2015). Conceptualizations of structural stigma are intentionally broad to encompass various forms and processes related to discrimination towards adults with SMI; however, such broad conceptualizations limit empirical assessment of structural stigma¹⁵. Second, data that can show development of policies based on stigma among policy-makers can be difficult to generate as policy-makers may provide socially desirable

¹⁵ FINIS framework proposed by Pescosolido and colleagues (2008) is one such example.

responses to questions related to stigma or rationalize their decisions through economic principles, such as balancing a state budget. Finally, mental healthcare policies in the U.S., both on the state and federal level, have become so complex that there are numerous policies influencing a single healthcare or social outcome for an adult with SMI (Grob, 1994; Grob & Goldman, 2006). However, conceptualizing the relationship between stigma, mental healthcare policies, and community participation can provide strategies to conduct empirical research in this area and reduce structural stigma. Thus, the aim of this study was to conceptualize the relationship between stigma, mental healthcare policy, and community participation.

5.2 Methods

5.2.1 Design and Methods

Qualitative research design using ethnography was employed to collect data for this study. The data were collected over a period of 6 months via interviews, fieldwork or participant observation, and document review of mental healthcare records of mental healthcare consumers and relevant local/state policy documents. Participants included mental healthcare consumers (n=18) and providers (n=16), along with policy stakeholders/experts (n=7).

Data collection sites. A 6-month ethnographic study was undertaken at 2 clubhouses (Journey and Odyssey, pseudonyms) in North Carolina (NC). Due to my previous research engagement and the dissertation's focus on assessing stigma via community participation or occupations, the clubhouse model was chosen as research site. The clubhouse model is a psychosocial rehabilitation model organized to support adults with SMI, referred to as members of a clubhouse. Membership in a clubhouse is voluntary and members "have equal access to every Clubhouse opportunity with no differentiation based on diagnosis or level of functioning" (Clubhouse International, 2016, p. 1). A clubhouse is comprised of various units such as

membership, administrative, and transitional employment. Members and staff or mental healthcare providers work together in various units to participate in numerous tasks (e.g., cooking, writing research grants, running a thrift store) to sustain a clubhouse. During the study period, Clubhouse Journey and Odyssey had an active membership of 104 and 88 members, and on average 32 and 19 members participated there on a daily basis, respectively.

The study was approved by the Institution Review Board at University of North Carolina-Chapel Hill (IRB#16-2920).

Fieldwork. I conducted fieldwork/participant observation at the two clubhouses and in the nearby communities for 6 months. During the fieldwork, I participated in typical activities of the clubhouse (5-6 hours/day for 4-5 days/week for 6 months) and in participants' daily lives. For example, I participated in a clubhouse social activity at a bowling alley, went to numerous lunches with member/s, and attended a local policy-level psychosocial rehabilitation collective meeting. Field notes were created for each field visit.

Interviews. I conducted semi-structured interviews, using an interview guide (Appendix C) to gather participants' perspectives on stigma, mental healthcare policy and community participation. Interviews were audio-recorded, with permission. Interviews lasted an hour on average (range=35-113 minutes). All interviews were transcribed verbatim.

Document review. Document review is a systematic procedure to analyze documents that are pertinent to a research question (Bowen, 2009). I reviewed members' mental healthcare records, clubhouse intervention notes, and local/state policy documents. The review consisted of reading, evaluation, and interpretation of the documents.

5.2.2 Participants

Members or consumers. Members (n=18) were recruited via purposive sampling. The eligibility criteria included: 1) age more than 18 years, 2) diagnosis of a serious mental illness, and 3) ability to communicate in English. To avoid potential confounders of stigma, adults with concurrent substance abuse and developmental disorders were not recruited. Eighteen members participated in the study (n=9 from each clubhouse). Informed consent was obtained from each participant. All but one member participant provided consent for release of mental healthcare information (Appendix B). Mean age for members was 49.23 years (SD=12.91) (Table – 1). Gender was equally distributed. Every participant had a primary diagnosis of Schizophrenia and 12 participants were taking psychiatric medication. Twelve participants identified as Caucasian or white and the rest as African-American or black.

Staff. Staff or service-providers (n=16) were recruited via convenience sampling and the eligibility criteria included: 1) age more than 18 years, 2) ability to communicate in English, and 3) currently providing services at a clubhouse. Most participants (n=12) identified as Caucasians while three participants identified as African-American and one as Iranian-American. Most participants identified as female, with 3 participants identifying as male. On average, staff have been working at the clubhouses for 5 years.

Policy experts. Policy experts (n=7) were recruited via convenience/snowball sampling with the following eligibility criteria: 1) age more than 18 years, 2) ability to communicate in English, and 3) having experience of informing, implementing, designing or evaluating mental healthcare policies. Experts in this study included a state legislator, a former director of a county mental healthcare system, two mental health law experts, a clubhouse board member, a consumer engaged in policy, and an expert with experience of examining state/federal mental healthcare

policies. To maintain participants' confidentiality, policy experts' demographics were not collected.

Table 5. Member participant demographics

Demographics	Consumers or members (n=18)
Age	49.23±12.91 years
Gender	Female=50% (n=9)
Race	White=66.6% (n=12) Black=33.3% (n=6)
Primary Diagnosis	Schizophrenia=100% (n=18)
Education	College=16.6% (n=3) Associates Degree=5.5% (n=1) Some College=27.7% (n=5) High School=22.2% (n=4) Some High School=16.6% (n=3) Unknown=11.1% (n=2)
Employment	Employed=16.6% (n=3) Transitional employment =5.5% (n=1) Self-Employed=5.5% (n=1) Unemployed=66.6% (n=12) Unknown=5.5% (n=1)
Housing	Rented apartment=50% (n=9) Group home=22.2% (n=4) With Family=22.2% (n=4) Unknown=5.5% (n=1)
Marital Status	Married=5.5% (n=1) Separated or Divorced=22.2% (n=4) Single or unmarried=55.5% (n=10) Unknown=16.6% (n=3)
Past Incarceration	Yes=5.5% (n=1) No=88.88% (n=16) Unknown=5.5% (n=1)
Currently taking psychiatric medicine	Yes=66.6% (n=12) No=16.6% (n=3) Unknown=16.6% (n=3)

5.2.3 Policy Context of Data Collection

During the study period, the state (NC) was under a settlement agreement with the U.S. Department of Justice (DOJ) regarding its mental healthcare services for failing to provide services in the least restrictive environment. In 2011, based on the complaints filed by consumers

and their advocates, the DOJ investigated the state's mental healthcare policies. The investigators reported that the state "plans, structures, and administers its mental health services system to deliver services to thousands of persons with mental illness in large, segregated adult homes, and to allocate funding to serve individuals in adult care homes rather than in integrated settings" (Perez, 2011, p.1). The investigation also highlighted that adult care homes acted as institutional settings, segregating residents and limiting their community participation/interactions. Further, the investigation highlighted that the state prioritized economic "investment in institutional settings at the expense of community-based settings" (Perez, 2011, p.2). After the investigation, a settlement was reached between the state and DOJ to improve community participation of mental health consumers via better housing, employment, and community mental healthcare support. Independent reviewers continue to conduct yearly assessments of the state's compliance with the settlement. Per the review report (Knisely, 2016), the state has yet to make fundamental shifts in its policies to better support community participation for its consumers. A policy expert interviewed for the study stated:

Records for over 300 people (consumers) were checked and only two people were diverted (to community-based care) out of the 300. So, the policies have not worked. As a matter of fact, the funding is set up such that and the arrangements are set up such that there's no possibility for diversion unless somebody just escapes basically the system.

5.3 Analysis

I analyzed data using open and focused coding. Open coding is a process of labeling chunks of data that are relevant to the research question (Corbin & Strauss, 2008; Saldaña, 2015). During this process, I consolidated the data into chunks that were relevant to the research, using categories such as "perspectives on stigma" and "influence of stigma on policies." Next, I used focused coding to identify patterns among the identified coded sets (Corbin & Strauss, 2008; Saldaña, 2015). In accordance with analytical ethnography traditions, during the third level

of analysis, I focused on interpreting codes to identify social processes (Snow, Morrill, & Anderson, 2003). This interpretive approach to data analysis led to the generation of the conceptual model. Finally, to strengthen the findings, member checking was employed by including a member participant's feedback on the findings.

5.4 Results

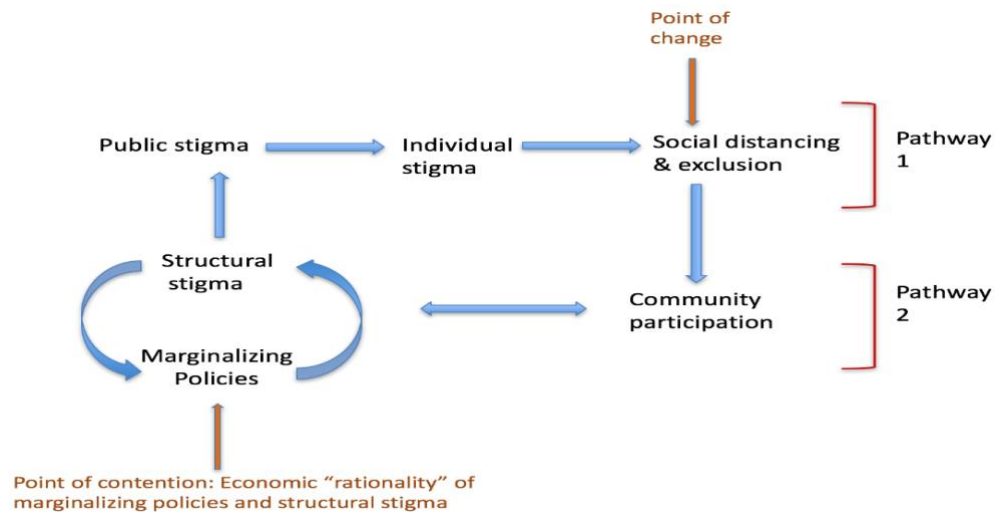


Figure 3. Framework conceptualizing relationship between stigma, policies, and community participation.

5.4.1 Pathway 1

The conceptual model (Figure 3) illustrates the relationship between stigma, policies, and community participation. Pathway 1 primarily discusses stigma from an interactional/individual level. Public stigma is defined as prejudicial and ill-informed views endorsed by the general public and individual stigma is defined as stigma invoked by an individual without mental illness during a social interaction (Pescosolido & Martin, 2015). The model assumes that individuals in contemporary society are born and brought up in a social reality where public stigma is rampant, as evident by portrayal of adults with SMI in media (Wahl, 1997). For example, in a study among secondary-school students, nearly half of the words used to describe mental illness were

derogatory or stigmatizing (Rose, Thornicroft, Pinfold, & Kassam, 2007). Regarding the role of media, a service provider shared her views:

...Media definitely contributes to socialization. Like we're socialized to believe that, you know, this population is dangerous to us.

Due to enculturation in a stigmatizing environment and the lack of mental health knowledge, many individuals learn to view mental illness as a stigmatizing attribute and tend to engage in social distancing or social exclusionary practices (Corrigan et al., 2007; Pescosolido & Martin, 2015; Link, Phelan, Bresnahan, Stueve, & Pescosolido, 1999). Social distancing entails scenarios where an individual will leave a social interaction to avoid interacting with an adult with SMI (Link et al., 1999). Such lack of interaction may not have any direct consequence for adults with SMI. However, during social exclusionary practices, there is an explicit desire to exclude adults with SMI from social participation, resulting in direct negative consequences for adults with SMI (Pescosolido & Martin, 2015). For example, community members may choose not to visit a thrift store operated by adults with SMI and this practice may not have any direct negative consequence for an adult with SMI. However, excluding adults with SMI from social activities, such as by not hiring them or limiting one's friendship with them, will directly lead to loss of economic or social capital for an adult with SMI (Link & Phelan, 2001; Link & Phelan, 2014). A member shared a life experience pertaining to this issue:

I had a fiancé that broke up with me when she found out that I took psychiatric medication. She said... "I don't want to wake up one morning with a knife in my back."

Such stigmatizing sentiments not just contribute to social distancing or exclusion of adults with SMI but also influence a member's or consumer's views about themselves, as one might view themselves as an "other" and stigmatize one's self (Corrigan & Watson, 2002; Estroff, Lachicotte, Illingworth, & Johnston, 1991). A service user shared her thoughts: "There is a

certain amount of stigma, you know. Society sees us as other and doesn't want to include us in their lives." Being characterized as "other" limits the general public's desire to participate with adults with SMI, negatively influencing their community participation. For instance, a member shared an experience of visiting a restaurant with his father and experiencing stigma and discrimination:

My father has PTSD from his... career in the military. There's this restaurant we go out every year when I go visit him... So this past time we were there and we sat at the counter up front at the bar where we always sit and ordered pancakes and my dad was telling our waitress that you know this is my son he's been visiting me and we come here every year and it's a tradition... My father sat inside and the place was busy at the moment and was very noisy and noise makes my father's PTSD intensify... and he doesn't like it. So we're talking to these two waitresses and trying to you know communicate this special thing we do this together every year. Eventually my father had to get up and walk out because the noise was bothering him so much... I was sitting at the counter by myself finishing my breakfast and it's so loud and this waitress is talking to me and I can't make out what she's saying and then all the sudden this other waitress that was behind the counter started shouting. First she said "he can't even hear you talking" to her... She said to the other waitress that "don't even pretend for a minute that you thought it was anything different. These two people are crazy." She shouted this.

The quote above highlights stigma experienced by individuals with serious mental illness in usual social activities, as the community members attribute shortcomings experienced during an interaction entirely on the illness, instead of other evident factors, such as the context of loud environment in this case.

With respect to individual stigma in the policy arena, a mental health law expert shared:

...In my perspective, one thing that has not changed much over the last 50 years is the stigma, stigma among general public and among the policy-makers.

The expert provided an example for his assertion. He shared an experience of a meeting with policy-makers and stakeholders regarding the right to information for individuals who are involuntarily committed.

She (policy stakeholder) stood up and she said 'we oppose this change' (right to information for the consumers) because, essentially, what she said was these are crazy

people and we don't know if they get this information and they see who the petitioner was or they see who the doctor was and they may get mad at them and then want to go kill them.

Another policy expert shared an example regarding stigma among policy stakeholders.

I think it was a joint legislative oversight committee for Health and Human Services and a woman who represents the industry portion of adult care homes referred to my boss and... said that if she (boss) wants those people living out in the community “I got some I want to send to live next door to her.” Like literally inciting fear of clients.

Dangerousness continues to be a fundamental element of stigma towards adults with SMI (Corrigan et al., 2002; Pescosolido & Martin, 2015). Like members of the general population, many policy stakeholders share such stigmatizing views. However, policy stakeholders’ stigmatizing views directly influence rights and services for the consumers. A consumer engaged in mental health policy work poignantly asked, “I think if you are afraid of somebody you're not going to help them. Don't you think?”

Consumer participation in policy decision-making. Stigmatizing views not only exclude consumers from general social participation, such views also help exclude them from policy-based discussions. Almost every policy expert in this study suggested that lack of meaningful inclusion of consumers in policy discussions helps sustain individual-level stigma among the policy-makers. A staff stated:

I think the state (legislators and policy stakeholders) has stigma about it you know and so it limits funds... and I think it's out of ignorance too because they're not aware of really what this thing is, what the disease is.

Here the staff highlights that stigma and ignorance among policy stakeholders directly influences the context and financial standing of mental healthcare. When asked if consumers have any influence on changing policies, a consumer engaged in mental health policy responded, “very little,” and elaborated:

...somebody's got to do it (advocacy) because most of those people on the state CFAC (Consumer and Family Advisory Committee) are there because of their bosses or they work for providers or they work for the MCO (managed care organization). They're not really representing consumers.

The consumer highlighted her frustration that even though there are advocacy boards present, they may be choosing their personal or professional interest over consumers' concerns. The consumer also shared her experience with stigma in the policy arena:

A state CFAC (official) who has a history of substance abuse and considers himself in recovery he looks down on people like me, and he says like "oh but you have a mental illness. I mean you're different from me"; and he's not the only one. There's lots of people there that way. It is as far as they're concerned, the lowest of the low of people are the ones that have a diagnosis of mental illness.

Such stigmatizing experiences can limit consumers or members who hope or want to participate in policy-based advocacy work, and thus, negatively influence mental health policies. Further, when coupled with public stigma, political environment sustains a space where policy-makers may not want to advocate for adults with SMI. A consumer engaged in policy discussions shared, "because of the stigma, they (policy stakeholders) don't want to be identified with something that's unpopular, pure and simple."

In the context of the policy arena, a direct result of stigma at the individual level and exclusion of adults with SMI from policy-based discussions is sustenance of structural stigma and marginalizing policies.

5.4.2 Pathway 2

Pathway 2 primarily discusses stigma from a structural-level perspective and its influence on community participation of adults with SMI. Regarding the relationship between the two pathways, a policy expert responded to the following question:

Interviewer: do you think the way the policies have been designed or continue to work at the state and federal level is reflective of how we as a community view adults with SMI?

Policy expert: Yes, it is. We still see them as a powerless group and it's so that we can set them aside and it's not humane.

Another policy expert shared:

I don't think that people fully accept that having a mental illness doesn't make you less human... A lot of folks really feel like “gosh I would be more comfortable if I didn't have to see them” and that's how we ended up with institutions in the first place. That's how we ended up with people in jail.

The two quotes above illustrate that stigmatizing attitudes on an individual level help maintain public and structural stigma, which threatens community participation of adults with SMI, such as via incarceration. Structural stigma continues to be an aspect of discussion within mental healthcare research; however, not as much attention has been paid to processes guiding structural stigma when compared to the mounting evidence regarding processes of individual-, public- and self-stigma, using a language of attributes (Pescosolido & Martin, 2015; Thornicroft et al., 2007). If the fundamental utility of structural stigma is to invoke interest in and study of discrimination towards this population, then a unit of analysis and intervention should, at least, inquire about the influence of policies on the social marginalization of this population. Thus, the concept of marginalizing policies is suggested. Marginalizing policies are conceptualized here as policies that negatively influence community participation for adults with SMI. Further, structural stigma and marginalizing policies are codependent. An example of marginalizing policies and sustenance of structural stigma is use of state dollars by NC to segregate adults with SMI in adult care homes (Perez, 2011). Regarding such exclusion from community participation, a policy expert shared:

There's not an accurate number of how many people were moved to those facilities (adult care homes) ... Maybe as many as 20,000 people. But the reason they went to the adult care homes was that there weren't services in the community so that's why they were sent there. Their guardians sent them there. General hospitals sent them there, without any other choice...

As evident from the quote, without state resources, community participation of adults with SMI was restricted to implicit institutionalization. Marginalizing policies are symbolic vehicles for sustaining both public and structural stigma, as such policies reinforce various stigmatizing stereotypes and limit community participation for adults with SMI. For example, the stereotypes related to dangerousness among the general public are reinforced by the marginalizing policies that perpetuate and sustain high rates of incarceration. This, when coupled with negative portrayal of mental illness in popular media, helps sustain the stereotypes of dangerousness (Baillargeon, Binswanger, Penn, Williams, & Murray, 2009; Draine et al., 2002; McGinty, Webster, & Barry, 2013; Wahl, 1997).

Policies also limited members' community participation by influencing care/intervention at the two clubhouses. According to clubhouse staff, state policies do not allocate funds to provide transitional employment (a time limited employment opportunity for members to gain vocational skills). More than half of the member participants (n=11) noted community participation (e.g., socialization and gaining employment) as a long-term outcome in their intervention plans. A member noted, "to decrease psychiatric symptoms by maintaining daily structure and socializing with others in an effort to increase overall health, and return to work" as a desired long-term goal. However, the lack of funding directly impacted staffs' ability to secure employment for the members, directly influencing the economic standing and community participation of the members. Only three member-participants in the study had formal employment and only one was on transitional employment. Out of two hundred active members at the clubhouses, only ten were on transitional employment and twenty-seven had independent employment. Further, policies also impacted mental healthcare at the clubhouse. A staff shared his frustration regarding economic challenges and its impact on membership engagement:

...if half of the budget isn't trying to fundraise (for Clubhouse sustenance) you know whether it's going to the county and asking for money or writing these grants, we can actually engage members in the work of the day and get reimbursed for just doing what we are supposed to be doing.

The staff highlighted that partly due to limited financial assistance via state dollars, the clubhouse struggles to effectively provide the services as they have to routinely choose between clubhouse sustenance and member participation.

5.4.3 Point of Change: Reducing Social Exclusion and Distancing

Based on participants' perspectives, the model proposes that social exclusion and distancing influence public stigma and mental health policies. Participants highlighted that there is a lack of understanding regarding mental illness among policy-makers, which negatively influences mental health policies.

Staff: I think our system's a little backward because you got people that are high up making the policies... don't even set foot in the facilities or agencies to see how they work and how they function, what they actually do. I think that's probably one of the biggest mistakes this state makes.

A member also shared similar concerns:

My outlook (regarding mental health policies) is not very good... I think that the people who are in the position making these changes or at the state level in the policy-making, I don't think they're in touch with what's going on the ground and around mental health community.

Therefore, a logical intervention is to reduce social distance and exclusion, specifically within the policy arena. Strategies that meaningfully increase consumers' participation in mental health policy discussion should be identified and advocated for. Further, social contact and mental health education interventions should be specifically targeted towards policy-makers, as they might address stigma (Mehta et al., 2015). For instance, it was not unusual to see Clubhouse Journey invite various policy stakeholders for a clubhouse tour. During a fieldwork day, I personally met a senator, who later sat in a meeting with the clubhouse staff and members to

discuss their ideas regarding mental health policy changes, both on local and state level.

However, the model acknowledges that these interventions may not be sufficient to change the marginalizing policies and the public stigma as other factors, such as economic challenges, can limit implementation of non-marginalizing policies.

5.4.4 Point of Contention: Economic “Rationality” of Marginalizing Policies and Structural Stigma

One of the policy experts stated that “first came the stigma and then came the economics.” Decision-making processes related to mental health policy are tied with economic concerns, both on the local and federal level (Grob, 1994; Grob & Goldman, 2006) and are, unfortunately, confounded by stigmatizing attitudes among policy-makers. A policy expert shared:

The attitudes of policy-makers towards Mental Health Services affect how much they prioritize them. So those attitudes of policy-makers affect policy.

A consumer engaged in policy shared similar views:

Consumer: ... it takes money to help people... and they (legislators and policy-makers) don't want to spend the money and I'm saying that's not just conservative that's a lot of so-called moderates and liberals too.

Interviewer: but why don't they want to...

Consumer: because of the stigma.

It is not uncommon to see budget cuts related to mental healthcare in the United States (Grob & Goldman, 2006). In North Carolina, the state has reduced the community mental health budget by significant margins while maintaining policies that implicitly institutionalize adults with SMI– a determining factor for the NC vs. DOJ settlement case. During the study period, I also followed mental health policy news. Between January – June 2017, there were thirteen states or communities in the U.S. whose policy-makers proposed to reduce or reduced mental health budgets, ranging from \$4-33 million in monetary cuts. Massachusetts was particularly noted for

its declining mental health budget while simultaneously increasing its state prison budget, a trend that is evident in other states as well (Demers, 2017; Domino, Norton, Morrissey, & Thakur, 2004). However, such policies are justified by the policy stakeholders on the basis of their economic rationality. During fieldwork, an MCO planned to close down one of its group homes, which housed three members of Clubhouse Journey. The closure was rationalized on the basis of economic limitations. However, during the same time period, the chief executive officer (CEO) of the MCO was receiving a salary that was \$413,331 above the state law guidelines (Craver, 2017). In North Carolina, a consumer usually pays around \$1,248/month to live in a group home, so \$413,331 equates to what six consumers would pay to live in a group home for 55 months. To look at the figure differently, the average yearly operating cost for a low management group home (with six consumers) is \$265,000 so \$413,331 would cover around 18 months of the operating costs¹⁶. The CEO rationalized his salary by suggesting that the MCO saved state dollars so he deserved that salary amount and that the MCO is not a state agency under guidance of state laws (Hoban, 2016). A service-provider shared her views on such rationalizations:

It's the short-term game of making an impact, in that if I can save money today, who cares if it saves money for tomorrow. I think it's strictly a budget decision. I don't think it has squat to do with quality of life or what would be most appropriate in terms of the treatment... the folks that are making policy level stuff, 9 times out of 10 they are not Healthcare folks... they feel like they do the best they can with the information they have, but at the end of the day they're trying to balance the budget, and it becomes a business decision.

Thus, it is partly due to such economic rationalities that availability of community mental healthcare resources is determined. Further, such economic rationality also influences individual level stigma. A service provider shared an interaction with a community member:

¹⁶ I contacted a group home manager to acquire current information regarding consumer payment and group home operating costs.

We had a meeting with someone to speak about a campaign to gain support, whether it be financial or informal in-kind donations, and the person was just like “I think it (psychosocial rehabilitation facility) should be out on the outskirts of the county... I think you need to make room for business” and to me it was a shock, and of course that was my first initial reaction. But there are people who are more economical.

The quote above highlights that economic rationality among community members can also limit community mental healthcare resources and thus, community participation for adults with SMI.

However, participants also shared that the economic rationality of mental health policies can be contested. A policy expert shared:

No, they (mental health policies) still don't make sense because they're not even fiscally rational. That's the really frustrating piece of this, and that even if you only care about the efficient use of public dollars, we're doing it wrong.

Another policy expert shared:

Policy-making is a fairly irrational process, unfortunately, and there are those who try to inject some rationality into it and some scientific evidence, you know, clinical expertise and legal activities, but you can't even put that. The political process is not only not rational, it's uneducated.

Thus, although mental health policies may seem economically rational in short term, they may not be economically rational for the consumers' care in long-term.

5.5 Discussion

Participants in the study were clear that stigma is manifested in mental health policy and that policy-makers/stakeholders often employ ill-informed and stigmatizing views about mental illness to design and implement policies, which negatively impact community participation of adults with SMI. Stigma is employed by individuals to enact discrimination, knowingly or unknowingly, towards those deemed as undesirable (Corrigan et al., 2004; Goffman, 1963; Link & Phelan, 2001; Thornicroft et al., 2007). Despite the increasing evidence that structural stigma influences the participation of adults with SMI, specific policy guidelines to address structural stigma are lacking. This influences mental health policy, as strategies to alleviate the struggles of

adults with SMI cannot be effectively designed/implemented without evidence-based policy guidelines. For instance: out of 4,679 bills in the U.S House of Representatives 2017-18 session¹⁷, there is only one bill that advocates for addressing stigma (H.R. 2677) and one to raise mental health awareness (H.R. 3073). Focusing on community participation and studying marginalizing policies can help analyze policies that perpetuate structural stigma.

However, a major source of contention to informing mental health policy is the economic “rationality” of mental health policies, as they continue to sustain the institutional practices and policies that marginalize adults with SMI. Such policies also sustain individual level stigma by making it seem rational (Corrigan, Watson, Warpinski, & Gracia, 2004). For example, many mental healthcare facilities and adults with SMI reside in neighborhoods that are economically struggling (Byrne et al., 2013). One of the clubhouses in the study was located in a neighborhood with sidewalks that had broken bottles, and houses and cars with broken windows. It is an individually economical decision to move-out of or not buy a home in such dilapidated neighborhoods as the housing prices are not likely to go up, providing diminishing returns on the investment. Given the limited economic resources, maintaining or increasing resources for one population may lead to diminishing resources for others. However, when such economic conservatism towards one specific population becomes a regular pattern (such as a continuous disparity in mental healthcare funding when compared to physical healthcare), across places and time, then the result is sustained discrimination and marginalization, contributing to adverse life outcomes for the stigmatized population (Callard et al., 2012; Evas-Lacko, Knapp, McCrone, Thornicroft, & Mojtabai, 2013; Mark, Levit, Vandivort-Warren, Buck, & Coffey, 2011; Mark, Levit, Yee, & Chow, 2014). Thus, evidence highlighting effective mental health policies as an

¹⁷ Information accessed on December 19, 2017 (<https://www.congress.gov/browse>)

economic investment and providing mental health knowledge can help policy-makers become advocates for better mental healthcare, that is, a top-down model for reducing stigma.

Public stigma and mental healthcare policies can be changed either via a top-down or a bottom-up approach. The bottom-up approach (Figure 4A) involves educating the general public, in hopes that some will become advocates for adults with SMI and help improve community (re)integration of adults with SMI, which could reduce public stigma. However, changing policies through a bottom-up model requires a sustained effort, which may not be possible in every community. Further, while social contact and education are suggested as interventions for reducing stigma, the interventions' long-term influence is debatable (Mehta et al., 2015). The evidence is also unclear if community members who are targeted with stigma-reduction interventions engage in sustained advocacy efforts for the population, which may lead to changes in structural stigma. However, a top-down model (Figure 4B), that is, sustained targeted efforts in reducing stigma among policy-makers, may help amend marginalizing policies and could change the stigmatizing discourse surrounding mental illness via successful community (re)integration of adults with SMI. A top-down model requires limited resources and directly reaches people who are responsible for policies and deemed as community leaders capable of changing community attitudes.

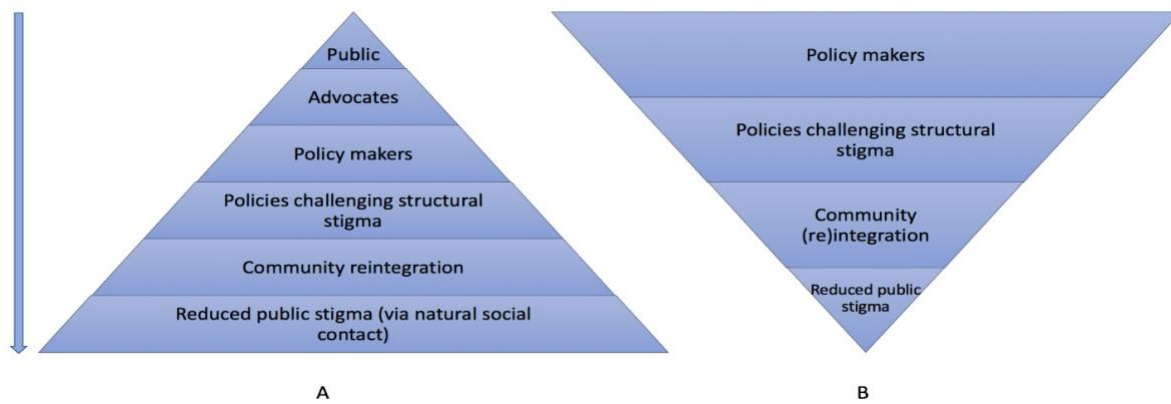


Figure 4. Bottom-up and top-down models to reduce stigma.

Ideally, both the approaches (bottom-up and top-down) would be implemented simultaneously to reduce stigma; however, economic restraints and existing stigma can hinder such simultaneous implementation in many communities. An example for reducing stigma via simultaneous employment of bottom-up and top-down models to reduce stigma is the Time To Change (TTC) campaign in England. The TTC campaign had endorsement from influential stakeholders to implement a population level stigma-reducing intervention (Henderson & Thornicroft, 2009). While the campaign helped in addressing prejudice and exclusion, it was limited in improving public support for community care towards the population (Evans-Lacko, Corker, Williams, Henderson, & Thornicroft, 2014). Further, while the UK government has funded the campaign, consequent changes in policies following the campaign are not yet evidenced. Further, in a study of public attitudes in the UK from 1994-2003, researchers suggested that mental health policy reform discussion may have contributed to deteriorating positive attitudes regarding PMI (Mehta, Kassam, Leese, Butler, & Thornicroft, 2009). Such findings highlight the influence of policy discussions in shaping public attitudes. Educating policy-makers enables them to educate community stakeholders and to advocate for the implementation of non-marginalizing policies, assisting in community (re)integration of adults with SMI. Successful community (re)integration challenges negative stereotypes and creates a natural social contact intervention that could reduce stigma. For example, members and staff at Clubhouse Journey routinely advocated for increasing their transitional employment fund from local policy-makers, and the advocacy efforts did allow a few members to gain employment and participate in nearby communities. This helped bring in potential employers to meet with other members, address stigma, and assist in community participation.

Finally, sustained and meaningful consumer involvement is required to address the exclusion of consumers from policy decision-making processes that ultimately influence their lives. During an interview, a consumer engaged in the policy arena shared that her voice or opinions were not always heard and meaningful participation mostly meant aggressively advocating for her peers with little impact, if any. Mental health policies dictate the lives of adults with SMI, who should have opportunities to inform these policies. Consumer involvement in healthcare has been strongly advocated (Green et al., 2014). However, policies dictate the care to begin with and those policies can be substantially improved if adults with SMI are meaningfully engaged in such processes.

Limitations. This study recruited consumers accessing mental healthcare and thus, perspectives from consumers who did not have access to mental healthcare were not collected. Perspectives from adults with SMI who do not have access to care could provide crucial information regarding the relationship between policies and community participation. Secondly, the participants were recruited from one state and the sample size, for each group, was relatively small. Further, specific federal policies were not evaluated for their influence on public stigma and community participation of adults with SMI. Triangulation during data analysis, via multiple analysts, was not employed. However, a member participant provided feedback on the manuscript and helped strengthen the findings, via member checking.

Future research. Foremost, research evaluating and addressing stigma among policy-makers/stakeholders is urgent. Policies dictate if a person can access resources for healthcare, housing, and employment. However, if policies are designed by individuals who lack mental health knowledge and have stigmatizing notions then resultant policies can restrict access to community participation. Existing interventions, such as education and contact, can be assessed

for their efficacy in reducing stigma among policy-makers. Another strategy is to expose policy-makers to mental healthcare facilities. During the fieldwork, it was not uncommon for Clubhouse Journey to invite policy-makers for a tour of its organization. It was due to such engagement that the consumers and the providers were able to contribute to local policy decisions.

Further, more research is required to quantify consequences of structural stigma. There is no doubt that stigma influences the lives of adults with SMI, but it can be difficult to quantify its effects. For example, it can be difficult to quantitatively capture the interaction between stigma among employers and the employment rate of adults with SMI. However, lack of quantification does not negate the fact that stigma leads to unemployment (Corrigan et al., 2004). Stigma is the glue that binds discrimination towards adults with SMI in various contexts together. Thus, stigma may have low weightage or account for low variance in one context, but cumulatively it can be more detrimental than other factors, such as symptomatology (Hinshaw & Stier, 2008; Pescosolido & Martin, 2015). Research utilizing the concept of marginalizing policies can help generate empirical evidence regarding structural stigma by focusing on policies and their influence on the outcome of community participation

5.6 Conclusion

During a public meeting regarding the state budget, a community member in the state of Vermont urged: “How can we as Vermonters, who consider ourselves to be compassionate, allow this inhumane treatment to happen for so long? Would we let someone who comes to the ER with a heart problem sit in the ER for a week or two? This is real proof that stigma is alive and well in Vermont... My son deserves to live in the community and not be locked up in a hospital” (McCullum, 2017). Such perspectives and findings from this study highlight the intersection between stigma, policies and community participation. The question is not if stigma

plays a role in construction of mental health policies, because, as the participants highlighted, it does. The question is: how can we reduce stigma and increase mental health knowledge among policy-makers to generate better policies that help consumers live their desired life in a community? Research is required to assess and address stigma among policy-makers and improve community participation for adults with SMI. Further, without addressing the issue of marginalizing policies, the cycle of stigma will continue. To end stigma in a community means that an adult with SMI can live a life of desired potential without being shamed and discriminated for his/her illness. To reach such an end, on a population level, opportunities to achieve a desired life are required and those opportunities can be embedded in a community, primarily by policy decisions to assist adults with SMI.

CHAPTER 6: PRINCIPLE OF GRADIENT RATIONALITY: REVISITING STIGMA AND CONCEPTUALIZING ITS GUIDING MECHANISM

The normal and the stigmatized are not persons but rather perspectives- Erving Goffman (1963, p. 138)

6.1 Introduction

Goffman's (1963) definition of stigma as "an attribute that is deeply discrediting" (p.3) is both a widely cited definition of stigma and a conceptual foundation for the contemporary research regarding stigma towards mental illness (Link & Phelan, 2001; Pescosolido & Martin, 2015). Present stigma research is steeped with evaluation of stigma via attitudinal assessments (using surveys) that rely on attributes attached to mental illness, such as unpredictability and dangerousness (Angermeyer & Dietrich, 2006; Pescosolido & Martin, 2015). However, much of this research is descriptive and provides limited guidance to address stigma on a personal as well as on a community or structural level (Estroff, Penn, & Toporek, 2004; Mehta et al., 2015; Pescosolido & Martin, 2015; Thornicroft, Rose, Kassam, & Sartorius, 2007). For instance: evidence regarding the long-term influence of standard interventions (such as psychoeducation and contact strategies) on reducing personal stigma is, at best, modest, and there is limited evidence about effective interventions that reduce structural stigma (Mehta et al., 2015; Pugh, Hatzenbuehler, & Link, 2015). Further, few survey studies assessing stigma account for social desirability within participant responses, thereby leaving findings vulnerable to flawed estimations of stigma and preserving conceptual limitations (Fowler, 2013; Pescosolido &

Martin, 2015; Thornicroft et al., 2007). However, revisiting knowledge regarding stigma as conceived by Goffman (1963) can provide guidance for future research.

Goffman (1963) defined stigma using a “language of attributes” (p. 3). However, he argued that to study stigma “a language of relationships, not attributes, is really needed. An attribute that stigmatizes one type of possessor can confirm the usualness of another, and therefore is neither creditable nor discreditable as a thing in itself” (p. 3). Goffman (1963) demonstrated that experiences of and strategies to manage stigma are dependent on the context of relationships and interactions¹⁸. For example, regarding the group divisions Goffman wrote: “stigma involves not so much a set of concrete individuals who can be separated into two piles, the stigmatized and the normal, as a pervasive two-role social process in which every individual participates in both roles, at least in some connections and in some phases of life” (p. 138). The few studies that have researched the role of relationships in stigma have corroborated Goffman’s assertions. For example, Jenkins and Carpenter-Song (2009) highlighted that experiences and consequences of stigma for adults with serious mental illness depend on the context of social interactions/relationships, such as work and romantic relationships. Finally, since research on stigma has historically relied on survey methodology, qualitative research collecting consumers’ perspectives on stigma is insufficient, hindering an in-depth understanding of social processes guiding stigma (Estroff et al., 2004; Kleinman & Hall-Clifford, 2009; Pescosolido & Martin, 2015; Thornicroft et al., 2007). Thus, the present study employed an ethnographic approach to understand the social process guiding experiences of stigma towards mental illness. Before elaborating on the study and its findings, it is necessary to review the lens via which mental illness is conceptualized and viewed by the general public.

¹⁸ Goffman’s emphasis on interactions was within the scholarly context of emerging theoretical significance of symbolic interactionism and constructivism during mid-20th century.

6.2 Definitions and Identification of Mental Illness

To examine stigma towards mental illness from the lens of relationships/interactions, it is integral to first examine what one identifies and defines as mental illness. Mental illness is defined within multiple domains (i.e., person, public, psychiatry, and policy) (Figure 5), which influences experiences of stigma, depending on which definitions are deployed. Estroff and colleagues (1991) demonstrated that a personal or self-definition of mental illness has more influence on illness identity than a psychiatric diagnosis, guiding experiences of stigma. Members of the general public also have their own distinct conceptions of mental illness, which influences their stigmatizing views (Granello & Granello, 2000). Definitions of mental illness also vary on the level of policy and psychiatry (Goldman & Grob, 2006; Ruggeri, Leese, Thornicroft, Bisoffi, & Tansella, 2000). Further, stigma towards mental illness and people considered mentally ill existed before there were scientifically defined criteria for mental illnesses, such as schizophrenia (Foucault, 1965; Kyziridis, 2005). Historically and in the public consciousness, mental illness is identified through its observed deviation from normative behavior or conduct (Baumann, 2007; Foucault, 1965). Such deviations from normative conduct are contextual and their identification depends on, what Goffman termed as, stigma symbols. Stigma symbols can be defined as signs or symbols that draw “attention to a debasing identity discrepancy” (Goffman, 1963, p. 43) and such symbols include, among others, physical appearance and conduct. For example, during an interaction, an individual may rely on stigma symbols, such as talking to one’s self, to categorize another individual as “mentally ill”, without confirming a person’s psychiatric diagnosis. Further, stigma symbols are dependent on the context and individuals, as interpretation of a symbol will vary based on the individual who carries a symbol and the individuals who observe that symbol. For instance: a famous actor

wearing disheveled clothes (stigma symbol) might not be stigmatized as much as an individual loitering while wearing the same disheveled clothes. Thus, mental illness, in an individual and social reference, is not a fixed entity but a concept with diverse and malleable definitions. Malleable definitions of mental illness allow for the identification of mental illness through a lens of deviance and stigma symbols, especially among members of the general public.

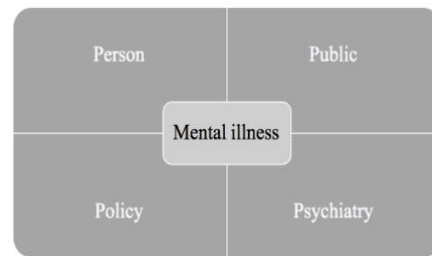


Figure 5. Domains defining mental illness.

6.3 Unreasonableness of Mental Illness: The Epicenter of Stigma

Much of the general public view adults with serious mental illness as unpredictable, dangerous, lazy, anti-social, and/or demented (Angermeyer & Dietrich, 2006; Rose et al., 2007). However, at the core of such stigmatizing characteristics is the refutable belief that individuals with mental illness are unreasonable or irrational¹⁹, an idea that is a historic remnant of the way mental illness has been conceptualized and viewed by the public (Foucault, 1965; Pilgrim & Tomasini, 2012). Foucault (1965) argued that unreasonableness was the basis for characteristics attached to mental illness: “in the general sensibility to unreason, there appeared to be a special modulation which concerned madness proper, and was addressed to those called, without exact semantic distinction, insane, alienated, deranged, demented, extravagant” (p. 66). Foucault (1965) added further: “We no longer understand unreason today, except in its epithetic form: the Unreasonable, a sign attached to conduct or speech...” (p. 83). When asked about the meaning of

¹⁹ For the purposes of this study, the terms reason and rationality are used interchangeably, and thus, the terms unreasonable and irrational are used interchangeably.

crazy (a stigmatizing and colloquial term used for mental illness), a consumer interviewed for this study responded: “I think it means insane and that means that somebody doesn't behave rationally or logically.” While stigma presents itself via the linguistics of prejudice, at the core of stigma is the belief that adults with serious mental illness deviate from social norms because they are unreasonable (Foucault, 1965; Pilgrim & Tomasini, 2012). Thus, irrationality or unreasonableness is an underlying assumption for stigmatizing attributes such as dangerous, unpredictable, and/or anti-social (Bates & Stickley, 2013; Foucault, 1965; Pilgrim & Tomasini, 2012).

Now that I have reviewed the social lens via which mental illness is viewed and what it is perceived to constitute, I will elaborate on the study and the proposed social process guiding the experiences of stigma.

6.4 Methods

6.4.1 Design and Methods

This study employed ethnographic methods to collect data over a period of 6 months via interviews, fieldwork, and document review of mental healthcare records and relevant local/state policy documents. Participants included mental healthcare consumers (n=18) and providers (n=16), along with policy stakeholders/experts (n=7). Study methods were approved by the Institutional Review Board at the University of North Carolina - Chapel Hill.

Data collection sites. A 6-month ethnographic study was undertaken at 2 clubhouses (Journey and Odyssey, pseudonyms) in North Carolina (NC). Due to my previous research engagement and the dissertation's focus on assessing stigma via community participation or occupations, the clubhouse model was chosen as research site. The clubhouse model is a psychosocial rehabilitation model organized to support adults with serious mental illness,

referred to as members of a clubhouse. Membership in a Clubhouse is voluntary and members “have equal access to every Clubhouse opportunity with no differentiation based on diagnosis or level of functioning” (Clubhouse International, 2016, p. 1). A clubhouse is comprised of various units including membership, administrative, and transitional employment. Members and staff or service providers participate in numerous tasks or occupations, such as cooking and writing research grants, to sustain a clubhouse. During the study period, Clubhouse Journey and Odyssey had an active membership of 104 and 88 members, and on average 32 and 19 members participated there on a daily basis, respectively.

Fieldwork. I conducted fieldwork at the two clubhouses and in the nearby communities for 6 months. During fieldwork, I participated in typical activities of the clubhouses (5-6 hours/day for 4-5 days/week for 6 months) and in participants’ daily lives. For example, I participated in a clubhouse social activity at a bowling alley, went to numerous lunches with member/s, and attended a local policy-level psychosocial rehabilitation collective meeting. Field notes were created for each field visit.

Interviews. I conducted semi-structured interviews, using an interview guide (Appendix C) to gather participants’ perspectives on stigma, mental healthcare policy and community participation. Interviews were audio-recorded with permission and lasted an hour on average (range=35-113 minutes). All interviews were transcribed verbatim.

Document review. Document review is a systematic procedure to analyze documents that are pertinent to a research question (Bowen, 2009). I reviewed consumers’ mental healthcare records, clubhouse intervention notes, and local/state policy documents. The review consisted of reading, evaluation, and interpretation of the documents.

6.4.2 Participants

Members. Consumers or members were recruited via purposive sampling. The eligibility criteria included: 1) age more than 18 years, 2) diagnosis of a serious mental illness, and 3) ability to communicate in English. To avoid potential confounders of stigma, adults receiving concurrent treatment for substance abuse and developmental disorders were not recruited. Eighteen members participated in the study (n=9 from each clubhouse). Informed consent was obtained from each participant. All but one participant member provided consent for release of medical information (Appendix B). The mean age for members was 49.23 years (SD=12.91) (Table – 1). Gender was equally distributed. Participants had a primary diagnosis of schizophrenia or schizoaffective disorder and 12 participants were taking psychiatric medication. Twelve participants identified as Caucasian or white and the remaining identified as African-American or black.

Staff participants. Service-providers or staff (n=16) were recruited via convenience sampling and the eligibility criteria included: 1) age more than 18 years, 2) ability to communicate in English, and 3) currently providing services at a clubhouse. Staff participants' roles included: unit leaders (membership or culinary), rehabilitative therapy specialist, and executive or assistant director. Thirteen participants identified as female and three participants identified as male. Twelve staff participants identified as Caucasians, three participants identified as African-American and one as Iranian-American. On average, staff had worked at the clubhouses for around 5 years.

Policy experts. State and federal policy experts (n=7) were recruited via convenience sampling with the following eligibility criteria: 1) age more than 18 years, 2) ability to communicate in English, and 3) experience informing, implementing, designing and/or

evaluating mental healthcare policies. Policy experts included a state legislator, a past director of a county mental healthcare system, two mental health law experts, a clubhouse board member, a consumer engaged in policy, and an expert with experience of examining state/federal mental healthcare policies. To maintain participants' confidentiality, policy experts' demographics were not collected.

Table 6. Member participant demographics

Demographics	Consumers or members (n=18)
Age	49.23±12.91 years
Gender	Female=50% (n=9)
Race	White=66.6% (n=12) Black=33.3% (n=6)
Primary Diagnosis	Schizophrenia=100% (n=18)
Education	College=16.6% (n=3) Associates Degree=5.5% (n=1) Some College=27.7% (n=5) High School=22.2% (n=4) Some High School=16.6% (n=3) Unknown=11.1% (n=2)
Employment	Employed=16.6% (n=3) Transitional employment =5.5% (n=1) Self-Employed=5.5% (n=1) Unemployed=66.6% (n=12) Unknown=5.5% (n=1)
Housing	Rented apartment=50% (n=9) Group home=22.2% (n=4) With Family=22.2% (n=4) Unknown=5.5% (n=1)
Marital Status	Married=5.5% (n=1) Separated or Divorced=22.2% (n=4) Single or unmarried=55.5% (n=10) Unknown=16.6% (n=3)
Past Incarceration	Yes=5.5% (n=1) No=88.88% (n=16) Unknown=5.5% (n=1)
Currently taking psychiatric medicine	Yes=66.6% (n=12) No=16.6% (n=3) Unknown=16.6% (n=3)

6.5 Analysis

I analyzed data using open and focused coding. Open coding is a process of labeling chunks of data that are relevant to the research question (Corbin & Strauss, 2008; Saldaña, 2015). During this process, I consolidated the data into chunks that were relevant to the research, using categories such as “perspectives on stigma” and “influence of stigma on policies.” Next, I used focused coding to identify patterns among the identified coded sets (Corbin & Strauss, 2008; Saldaña, 2015). In accordance with ethnographic tradition, my third level of analysis focused on interpreting data in a manner that helped identify social processes (Snow, Morrill, & Anderson, 2003). This interpretive approach to data analysis led to the generation of the social process presented below. Finally, to strengthen the validity of findings, member checking was employed to elicit a participant’s (clubhouse member) feedback on the findings.

6.5 Results

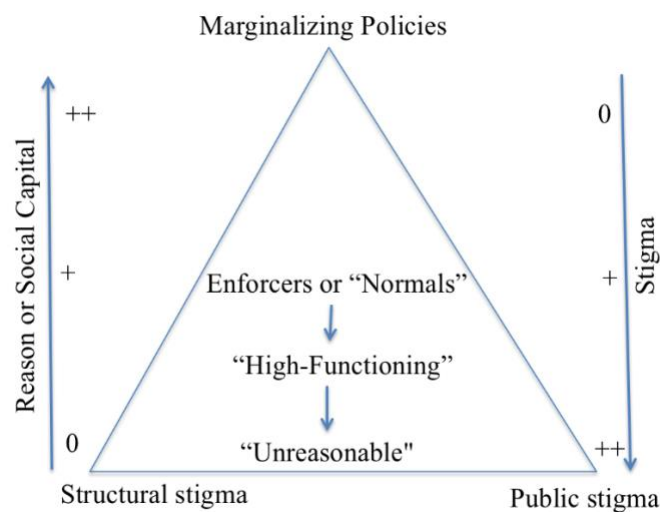


Figure 6. Principle of gradient rationality: A social process guiding experiences of stigma

Data analysis led to the identification of a social process termed the principle of gradient rationality (PoGR) (Figure 6). Briefly, the principle suggests that, during an interaction, individuals can be placed in a hierarchy of three roles/categories (“unreasonable,” “high-

functioning,” or “normal”) based on their measure of non-normative behavior or unreasonableness. The lower one’s position in the hierarchy, the more likely one is to experience stigma. There are three components to the principle: 1) categorization via stigma or status symbols; 2) movement via exchange of social capital; and 3) institutionalization of stigma via interactional stigma.

6.5.1 The Categories and Categorization via Stigma or Status Symbols

Humans categorize or label other humans based on their differences or sameness, judging on the basis of both physical and social attributes or symbols, such as skin color and clothing (Crocker & Lutsky, 1986; Goffman, 1963). Goffman (1963) defined stigma symbols as pieces of social or physical information that place an individual in a stigmatized category, and status symbols as symbols that place an individual into a desirable category. During fieldwork, a clubhouse volunteer shared that she was generally able to use social symbols, such as clothing and conduct, to distinguish between members and staff, despite being in a setting where no official patient category exists. A member shared her views regarding categorization:

It (stigma) just goes down to the person, not the person who has an illness but the person who is judging... it has to do with them and I think the reason why they do is just because that's just our (human) nature...

Since a psychiatric diagnosis is not visibly identified, stigma symbols or non-normative conduct assists in categorizing someone as “mentally ill,” which then leads to stigma. On an interaction level, stigma towards mental illness is stigma towards non-normative behavior or unreasonableness, as a member shared:

I think it (stigma) is mainly caused because there are ways that people think (other) people need to learn to interact. That everybody needs to interact and somebody that does not interact in that way, he is not something that people want to be and that (behavior) offends a large amount of people and that's where the stigma comes from.

Another member added:

I think it's (stigma) mainly against people who (with) their outward appearance or their motions or behavior are unusual and sometimes threatening and it makes people uncomfortable.

At the heart of the PoGR is the measure of unreasonableness or irrationality or non-normative behavior. Goffman (1963) stated that “the role of normal and role of stigmatized are parts of the same complex, cuts from the same standard cloth” (p. 130). I argue that cloth to be the measure of unreasonableness, as Goffman (1963) stated, “it can be assumed that a necessary condition for social life is the sharing of a single set of normative expectations by all participants...” (p. 127). Regarding presence of a measure, a member shared

There's a difference between people with mental illness and people that don't have them and there's degree (measurement) of it cuz I think nobody without mental illness is perfect. I mean everybody has some degree of it but not everybody has a diagnosis.

Regarding the measure of unreasonableness, a member used the term “effectiveness” to highlight the idea:

When people see that this person is high-functioning and doing so well that they don't even look like they have an illness. But I feel like nobody should be judged based on their effectiveness.

Here the member highlighted effectiveness in functioning or adjustment to normative expectations as a measure of identifying and categorizing mental illness into categories such as high- or low-functioning. During a fieldwork day, a potential member and her mother toured Clubhouse Journey. When the tour finished, before asking staff how the clubhouse can help with housing and employment, the mother said “you know she's (potential member) high functioning and sometimes people don't even know that she has a psychiatric diagnosis but the anxiety cripples her. Would you help her in finding employment and housing?” The statement highlights public members' (including family members) views about individuals with serious mental illness who are able to manage their symptoms or adjust to the illness. Thus, based on measures of

unreasonableness or adjustment to the illness during everyday interactions, individuals are categorized within the hierarchy.

During an interaction, an individual can be categorized as either an unreasonable person, a high-functioning person, or a normal person (also referred here as an enforcer)²⁰. However, for individuals who disclose their psychiatric diagnoses, others are mostly skeptical towards the rationality of their behavior by equating their behavior with their personhood or identity as an adult with serious mental illness²¹. Thus, at the bottom of the hierarchy are adults with serious mental illness, as they are considered inherently unreasonable in their behavior/conduct. A member shared his views regarding this aspect:

I mean when I first came here I would only interact with staff. With them (staff) there is a normal social order and etiquette but members can be unpredictable and I don't know how to react sometimes.

The quote above also highlights that even a consumer may question the reasonability of members' behavior and choose not to interact with them. Highlighting the stigmatizing attribute of unpredictability, the same member further shared:

When you're talking with mentally ill people and this might be a stigma thing but social rules and etiquette go out the window you don't know what they're going to say.

In the PoGR model, the category of “high-functioning” is above the category of unreasonable. The distinction between high-functioning and unreasonable here is not based on neurocognitive functioning. With regards to stigma, functioning is related to adjustment of one's conduct towards normative behavior. Goffman (1963) discussed “good adjustment” as a way to

²⁰ It is important to note that even though I have used person-based language, unreasonable, high-functioning, and enforcer are perspectives or roles that are dependent on contextual factors.

²¹ Unless judged to be reasonable via display of some social capital, an aspect discussed later in this paper.

avert stigma and cohere one's self to the category of normal (p.121). Regarding adjustment, a member shared:

I don't view it (stigma) as intrinsic to illness cuz I think a lot of times some people with a mental illness figure out a way to adapt (to) it.

Within the hierarchy of categories, the better one's adjustment, the less stigma will be communicated and experienced. Adjustment techniques were evident among "high-functioning" members in the clubhouse, as a staff shared:

I think we have higher functioning members that they will come in but they don't want their picture to be out there. They don't want to be associated on the website or they don't want people to know. They still want to use Odyssey (clubhouse) as a support system but they don't want anybody to know because there's an embarrassment.

In the context of the clubhouse, many members categorized as "high-functioning" cared about their adjustment in the outside community and knew that such adjustment required distance from places known to be accessed by individuals who are stigmatized. Since stigma is dependent on signs or symbols displayed during an interaction in a particular context, a consumer who adjusts well towards a given norm will display fewer stigma symbols, and consequently, evoke and experience less stigma. Further, the adjustment is inversely related to symptomatology or neurocognitive functioning as increased symptomatology can increase the likelihood of social penalties, such as unemployment, hospitalization, homelessness and/or incarceration, making one more vulnerable to stigma (for e.g., Draine, Salzer, Culhane, & Hadley, 2002; Hafner, Löffler, Maurer, & Hambrecht, 1999).

Finally, the top of the hierarchy is represented by "normals" or enforcers. To be placed in the category of normal means that one behaves or conducts oneself in accordance with normative expectations, and thus, will not experience stigma derived from mental illness. However, the role of normal is not restricted to one's own behavior or conduct but also includes enforcement of

normative expectations. Stigma requires a stigmatizer or enforcer to exist and that enforcer has two functions: to keep himself or herself familiar with the normative rules of conduct so s/he is not stigmatized and to enforce those rules in various settings. Without enforcement of the rules, transgression of social rules will go unnoticed and a stigmatized person will not be stigmatized for their transgression (Goffman, 1963). It is to avoid transgression that one aims to hide his/her mental illness via normative conduct (Goffman, 1963; Jenkins & Carpenter-Song, 2009).

Further, enforcement of rules may not be an explicit ambition of the enforcers or the normals but an implicit desire (Goffman, 1963; Link & Phelan, 2014). Regarding the idea of enforcer, a staff shared her views by highlighting absence of an explicit “enforcer” and the voluntary nature of participation in the clubhouse model:

...because there's no enforcer to make you have to do anything, it's like if you want to come and just want to sit and chill all day it's okay...

Through the quote, the staff highlighted that members/consumers have more agency in a clubhouse model than in other mental healthcare settings, as no one is explicitly enforcing any expectations of normative rules for participation. Other settings frequented by member participants often included explicit enforcers, as highlighted by a staff:

One of the members is having trouble with her group home. I mean she's in a wheelchair and then because of her meds she has to pee frequently and she is not always on time. The group home seems to be using punitive strategies to punish her. I mean they don't let her come here the next day if she pees herself and they have to clean up.

While the instance above highlights an explicit example of enforcement of rules, in usual scenarios such enforcement is more implicit and relates to expectations of “normal” conduct from the general public. For example, a member shared,

My thing is when we go out as a group I know we (are) looked at differently, you know. We are frowned down upon because we're different, you know.

For instance, a Clubhouse Journey staff shared an experience of visiting a local coffee shop and experiencing stigma and discrimination:

we were celebrating an event and in order to celebrate the event we went to a local coffee shop and there were probably 13 or so of us at the time and there were two people behind the counter at the coffee shop. Apparently it was overwhelming for them and so they got angry real fast and then one of our members interrupted and kept asking for a glass of water because it was time for him to take his medicine and for him he has to take it on the dot... so he kept asking and he got yelled at by the staff and the staff basically told him off and clearly said "I'll get you your water when all these people have had their coffee then you'll get your water so stop asking until then..." I don't see them doing that to other customers... It was clearly discrimination because they knew who we were (a clubhouse that assist adults with SMI).

Finally, the categorization and resultant stigma is dependent on the context of interactions and relationships. Goffman (1963) noted that it is possible for signs or symbols that "mean one thing to one group to mean something else to another group, the same category being designated but differently characterized" (p. 46). Thus, categorizations are not permanent or ubiquitous. For instance, while being of brown or black skin color can be stigmatizing during certain times and at certain places, the same skin color can also be a sign of prestige or pride at other times and places. Similarly, a person who is "unreasonable" during one interaction can be an "enforcer" during another.

6.5.2 Movement within Categories via Exchange of Social Capital

During fieldwork, the following interaction highlighted the contextual nature of categorization.

While we (two members and I) were talking outside the clubhouse, Jennifer²² (staff) walked past us and said "you are still talking. Find some work." We did not say anything. As soon Jennifer entered the house, Julio (member) said "don't listen to that woman, she's crazy." Another member, Jean said, condescendingly, "she just can't stand people who rock the boat."

²² Participant pseudonyms, instead of real names, are used throughout this dissertation.

Through this interaction, it was clear that unreasonableness, in its linguistic form of “crazy,” is a relative term and can be used to defame, disgrace or stigmatize individuals who do not have a psychiatric diagnosis by those who have such diagnosis²³ (Estroff, 1981). Further, just like non-normative behavior is used as a source for stigma among individuals without psychiatric diagnosis, normative behavior can become a source for stigma within a group that is usually identified as non-normative, highlighted by the statement “she just can’t stand people who rock the boat.”

It is noteworthy that it was only in the absence of a “normal” that a normal was stigmatized. In order to actually move up the hierarchy or demonstrate defiance towards stigma, an individual who is labelled as “unreasonable” would have to demonstrate some social capital or normative reason via conduct. A member’s view highlighted this aspect:

I would use stigma as when people are behaving in a way that really offends the people and people that are offended will shun them. In many cases, they (adults with mental illness) don't have the resources to be able to hide it [non-normative behavior], they don't have the training or the knowledge to not do it (non-normative behavior)...

This quote demonstrates the importance of having resources or social capital to avoid stigma. Goffman (1963) discussed how such exchanges can ward off stigma: “the more the stigmatized individual deviates from the norm, the more wonderfully he may have to express possession of the standard subjective [normative reason or conduct] self if he is to convince others that he possesses it...” (p. 116). Social capital is necessary for normative conduct as without the means to display or learn normative conduct, one cannot convincingly display or perform it (Bourdieu, 1998; Goffman, 1963). Additionally, social capital is displayed via symbols as well. Symbols that highlight possession of social capital include material assets (such as clothing or money) and

²³ As Goffman (1963) said: “The normal and the stigmatized are not persons but rather perspectives” (p. 138).

cultural assets (such as being a teacher or businessman). Both material and cultural assets comprise social capital which helps identify one's place in society, and thus, determine one's vulnerability towards experiences of stigma (Bourdieu, 1998; Goffman, 1963). For instance: a white male diagnosed with schizophrenia and employed as a university professor will have different experiences of stigma as compared to a black woman with schizophrenia working at a local coffee shop. A member who is considered as a high-functioning consumer shared his perspective on having social capital and not experiencing stigma:

I've never been in that (stigmatizing) situation before because of my upbringing and my history (as a white male college graduate with access to family/social and healthcare resources) so I have never been the vulnerable person to deal with that (stigma) so that's why I guess, you know, why I don't know much about stigma.

The same member further shared his perspective on how social capital helps mitigate stigma:

I know what the rules are and the etiquette and stuff like that... I've become mentally ill but with a social conscience... like social awareness so I still have that...

Thus, having social capital can help shield one from stigmatizing experiences and be considered as high-functioning, if one simultaneously employs adjustment techniques. The influence of social capital on avoiding stigma was also evident during fieldwork. On one particular fieldwork day I attended a clubhouse meeting with staff, members, a county official, and a business expert hired by Clubhouse Journey to help in their fundraising campaign. During the meeting, the business expert looked at Cheryl (a member who is part of the board governing the clubhouse) and said, with great surprise, "this one right here is great. She is really smart and well-spoken and I didn't even know that she's a member." Here, the member (Cheryl) had to go through the process of being a board member, and consequently gain social capital, to not be perceived as a member/consumer.

Finally, if a stigmatized person (such as an individual experiencing mental illness) gains a higher social position (such as of a teacher) then s/he might be regarded as an exception to the group of adults with serious mental illness. As Goffman (1963) highlighted: “when a stigmatized person employs this stance of good adjustment he is often said to have a strong character or a deep philosophy of life, perhaps because in the back of our minds we normals want to find an explanation of his willingness and ability to act this way” (p. 121). A staff member, who routinely participates in advocacy efforts in community, further highlighted this idea:

In the US, even if this one person with schizophrenia goes out into the community (for advocacy) and everybody learned and knows who this person is, people start to learn that he will be an exception. They are still going to treat the next person with schizophrenia the same (with stigma and using stereotypes).

Thus, public stigma towards a group is not necessarily diminished via social contact with “well-adjusted” members of a stigmatized group, as larger institutions maintain structural stigma that keeps a majority of the population in socially disadvantaged positions, reinforcing the public stigma.

6.5.3 Institutionalization of Stigma via Interactional Stigma

The primary functions of individual-level stigma are discrimination and social control on a population level (Corrigan, Markowitz, & Watson, 2004; Goffman, 1963; Link & Phelan, 2001; Link & Phelan, 2014; Thornicroft et al, 2007). A policy expert shared an example of this aspect:

I left-- I think it was a joint legislative oversight committee for Department of Health and Human Services-- and a woman who represents the industry portion of the adult care homes referred to my boss and... said that “if she wants those people living out in the community I got some I want to send to live next door to her.” Like literally inciting fear of her clients...

The interaction above highlights the influence of individual-level stigma (by a policy stakeholder) on structural (housing) opportunities for adults with serious mental illness. In this

example, social control is implicit as the policy stakeholder, relying on stigmatizing notions, is opposed to community integration of adults with serious mental illness. The policy expert further elaborated on the influence of stigma on the mental healthcare system:

Policy expert: I don't think that we have a system that contemplates that people could be stabilized, return to the community after a crisis, work, engage in education, and have a family life. There's still very much a presumption that if you experience significant and persistent mental illness or even if you experience mental health crisis, the expectation is that you will be single, live alone, not be engaged in work, and that managing your mental health will be a full-time job.

Interviewer: but why do you think that is the case?

Policy expert: I think a lot of that is stigma and lack of understanding.

A member also shared similar views:

The public mental health system is so small because the state wants it that way. The amount of resistance to developing community programs is not really estimated but is assumed to be breathtakingly deep. In other words, if we're talking about stigma that is where the primary focus of it is because the system has not viewed us as capable of providing any successes whatsoever.

Thus, the stigmatizing notion of assuming adults with serious mental illness as incapable of being productive members of a community implicitly contributes to inefficiencies within the mental healthcare system.

Further, social control and discrimination is maintained via structural stigma, public stigma, and marginalizing policies²⁴. For instance, regarding employment, media campaigns to reduce public stigma can help decrease structural stigma by decreasing stigma among employers; however, many adults with serious mental illness will require policy support for gaining employment skills or housing in a community to approach an employer and/or be competitive for employment. A policy expert shared his views regarding the intersection of stigma, healthcare and policies:

²⁴ Marginalizing policies are conceptualized here as policies that negatively influence community participation for adults with serious mental illness. This concept is elaborated in Chapter - 5.

It was long problematic and I assume still to some extent is, for example, to get health insurance that would cover mental health services, which meant limited funds to provide mental health services and that was based, I think, on the view (that) mental health services are less important, less valuable and it's sort of stigma talking as to why that was the case.

Public and structural stigma are a representation of individual interactions and relationships as stigma at an individual level maintains or bolsters stigma within institutions and public discourse. While the PoGR is starkly evident in individual interactions, its implicit constitution at larger levels helps maintain structural stigma and marginalizing policies. A consumer engaged in policy work shared her views, highlighting the presence of the PoGR in larger domains:

Regarding the hierarchy of unreasonableness: A State CFAC (Consumer and Family Advocacy Committee) official who has history of substance abuse and considers himself in recovery, he looks down on people like me and he says like "oh but you have a mental illness. I mean you're different from me" and he's not the only one. There's lots of people there that way. As far as they're concerned the lowest of the low of people are those who have a diagnosis of mental illness.

Regarding the influence of social capital: Because of the political background I have and the interest that, you know, this (advocacy) started not just because of me but my whole family has a history of mental illness. I mean I wanted to do this but I couldn't have done it if I didn't have the political contacts (social capital).

It is the preservation of the PoGR within institutions that helps maintain the stigma in larger contexts. Stigmatizing notions allow skepticism towards ideas provided by adults with serious mental illness, thereby inhibiting consumer participation in mental healthcare policy decision-making, which contributes to flawed policies and structural stigma (elaborated in Chapter 5). A consumer engaged in policy shared her views regarding stigma on an interactional level within the policy arena:

Interviewer: Have you ever been stigmatized while advocating for policies in the state?
Consumer: absolutely!... I mean it's not so much a matter of, you know, overt actions but a lack of inclusion... So, I don't think it's as much as them getting up and saying bad things about people that are consumers. It's just like "we'll (policy-makers) just ignore them (consumers) because we don't like what they say anyway."

Thus, individual-level stigma, maintained via the PoGR, contributes to structural and public stigma, which then further strengthens individual-level stigma (elaborated in paper 2).

6.6 Discussion

The PoGR illustrates that while illness is integral to experiences of stigma, the idea of unreasonableness varies depending on the context, and consequently, experiences of stigma will differ on the basis of context (Estroff et al., 1991; Jenkins & Carpenter-Song, 2009; Pilgrim & Tomasini, 2012). However, contemporary stigma research primarily relies on survey methodology using attitudinal measurements that obfuscate the variability of experiences of stigma and also the variability of individuals who experience serious mental illness. A person's experience and anticipation of stigma depends on one's cultural and ethnic background, which influences one's internalization of stigma (Abdullah & Brown, 2011; Link & Phelan, 2001; Pescosolido et al., 2008; Oexle et al., 2018; Sirey, Franklin, McKenzie, Ghosh, & Raue, 2014). Yet, evidence suggests that socio-demographic characteristics are not significant in influencing internalized-stigma (Livingston & Boyd, 2010; Pescosolido & Martin, 2015). Current stigma measurements are limited in acknowledging socio-economic differences in experiences of stigma as they view consumers on the basis of their stereotypical attributes. Future research utilizing the PoGR can help identify strategies to better understand and quantify stigma while acknowledging variability in the experiences of stigma.

Scholars have also argued that the study of stigma has primarily been conducted using an individualistic focus, via a language of attributes (Estroff et al., 2004; Kleinman & Hall-Clifford, 2009; Pescosolido & Martin, 2015; Thornicroft et al., 2007). Such ideas may portray a stigmatized person as a victim having an undesirable attribute (Fine & Asch, 1988; Link & Phelan, 2001). However, looking at stigma via a language of relationships, as Goffman (1963)

proposed, means that for every stigmatized individual there is at least one stigmatizer. The PoGR clearly outlines the contextual nature of stigma and places a stigmatized individual within a hierarchy where stigma cannot be conceptualized without a stigmatizer. Further, the PoGR also contends that each individual, irrespective of psychiatric diagnosis and depending on a context, is not a passive receiver of stigma but a social being with agency to stigmatize others. For example, “crazy” as a term can be used by consumers to enforce rules of normalcy while defaming a fellow consumer (Estroff, 1981).

Further, as contemporary stigma research has relied on a language of attributes, the limitations of such understanding has influenced intervention research. Current evidence indicates that two widely utilized interventions, psychoeducation and contact strategies, are limited in their long-term influence on changing public attitudes (Mehta et al., 2015). Similar to stigma measurement, the efficacy of interventions is also measured via survey methodology that 1) rarely accounts for social desirability, leaving the findings vulnerable to an over-estimation of the interventions’ efficacy, and 2) subsumes variability of stigma experiences among consumers, which may reduce interventions’ effectiveness for people from minority social groups, such as African-Americans with mental illness (Fowler, 2013; Oexle et al., 2018). Understanding stigma from the perspective of the PoGR provides guidance for future research. The principle suggests that an individual who adjusts better to normative conduct might be considered as an exception to the stigmatized group. Perhaps, it is this notion of exceptionalism that limits the efficacy of social contact strategies, as community members think of consumers participating in social contact interventions as an exception. In the absence of structural changes, the notion of exceptionalism limits changing public attitudes as community members do not change their ideas regarding the population but only for a select minority of the population, who are able to adjust

well via social capital or resources. Further, as social capital is integral to stigma experiences, the PoGR highlights that, broadly, certain minority groups will experience more stigma than normative groups (Abdullah et al., 2011; Oexle et al., 2018). Thus, future intervention research should collect perspectives from a diverse group of consumers and community participants to better understand the influence of existing interventions and the mechanisms via which the interventions' impact can be sustained over time. Further, as socio-economic capital is integral to challenging stigma, it is necessary to address structural stigma because it continues to limit socio-economic capital, and thus, community integration for adults with serious mental illness (Corrigan et al., 2004; Draine et al., 2002; Link & Phelan, 2014; Pugh, Hatzenbuehler, & Link, 2015). Thus, future research should also focus more on understanding and addressing structural stigma, in order to integrate adults with serious mental illness into communities.

Finally, this study of stigma owes a significant debt to the clubhouse model. The clubhouse model relies on members' agency and staff-member relationships to reduce stigma and facilitate psychiatric recovery, providing the context and opportunity to study stigma through the lens of relationships (for e.g., Conrad-Garrisi & Pernice-Duca, 2013). For instance, unlike various mental healthcare models, consumers at clubhouses have the agency to choose whichever staff they want to work with and what tasks they want to work on. The clubhouse model views consumers in equal capacity with service-providers, and thus, humanizes consumers as active social beings capable of dismantling stigma in the community while simultaneously being capable of stigmatizing others. For instance, members sometimes stigmatized staff for being unreasonable or members stigmatized other members for being "crazy." As evidence indicates, stigma towards mental illness is prevalent across space and time, and exists even within the context of mental healthcare (Henderson et al., 2014; Pescosolido &

Martin, 2015; Thornicroft et al., 2009). However, the context of clubhouse allowed for an in-depth analysis of social processes related to stigma towards mental illness, by gathering perspectives from the members and observing equitable member-staff relationships that undergird the functioning of the clubhouse model.

Limitations. This study recruited consumers accessing mental healthcare, and thus, perspectives from consumers who did not have access to mental healthcare were not collected. Further, while the principle suggests that ethnic background can expose an adult with serious mental illness to additional stigma, due to the lack of participants from minority backgrounds and the limited focus of the study on stigma related to other demographics, the intersectionality of stigma and race/ethnic identity-based discrimination was not observed. Such data could have provided additional support to the principle's emphasis on the influence of social capital on experiences of stigma. In addition, participants were recruited from one state and the sample size, for each group, was relatively small. Finally, triangulation during data analysis, via multiple analysts, was not employed. However, a member participant provided feedback on the manuscript and helped strengthen the findings, via member checking.

6.7 Conclusion

Within the public imagination, mental illness is a largely invisible condition that is identified on the basis of deviancy from normative conduct (Baumann, 2007; Pilgrim & Tomasini, 2012). The measure of distance from normative conduct determines one's exposure to and experiences of stigma. The PoGR highlights a social process for understanding and studying stigma as it embeds stigma experiences within the context of social interactions and relationships, an area that is severely understudied in stigma research (Kleinman & Hall-Clifford, 2009; Pescosolido & Martin, 2015; Thornicroft et al., 2007). Research in other settings is

required to study the relevance of the PoGR across contexts. Further research employing PoGR can also help develop instruments that can appropriately measure stigma in a way that acknowledges a context and an individual's experience. Finally, while PoGR is primarily applicable to social interactions, it illustrates that stigma at an interactional level preserves stigma at the structural level, requiring more research regarding social processes pertaining to structural stigma.

CHAPTER 7: DISCUSSION AND CONCLUSION

7.1. Introduction

The earlier chapters in this dissertation provided the rationale for this dissertation study, outlined the methodological approach employed to collect and analyze data, and presented the key findings of this study. In this chapter, I will briefly discuss the key findings highlighted in previous chapters, discuss the nuances and interconnectedness of the findings through an integrated discussion section, and outline their implications for the stigma research and the occupational science scholarship.

7.2 Study Overview

The purpose of this dissertation study was to identify the social processes guiding experiences of stigma and occupational engagement (mental healthcare and community participation) for adults with serious mental illness. The study employed an ethnographic approach including interviews, fieldwork/participant observation, and document reviews at two clubhouses in North Carolina. A total of 18 adults with serious mental illness or members and 16 clubhouse staff or service providers were recruited for the study and their perspectives on the topics of interest, such as stigma and mental healthcare, were collected over a period of 6 months. Additionally, seven mental healthcare policy experts were interviewed to gather their perspectives on the influence of stigma on mental healthcare policies. Data were analyzed using open and focused coding along with analytic interpretation. The analysis generated three papers that illustrate: 1) a social process (moral economics of occupations framework) that conceptualizes occupations as assets and their relevance in maintaining institutional practices; 2)

a conceptual framework highlighting the relationship between stigma, community participation, and mental healthcare policies; and 3) a social process (principle of gradient rationality) guiding experiences of stigma on an interactional level.

7.3 Integrated Discussion

This dissertation used occupation as a unit of analysis to better understand social processes related to occupational engagement or participation and stigma towards mental illness. Contemporary stigma research continues to study stigma primarily via a language of attributes, perpetuating the conceptual limitations highlighted in previous chapters, such as overlooking the variability of stigma experiences among individuals (Estroff et al., 1991). This study highlights that stigma is enacted through occupations. For example, the general population or mental healthcare providers may inaccurately assume (via stigmatizing notions) what an adult with serious mental illness can or cannot do (Henderson et al., 2014; Sakiyama et al., 2010). Such assumptions are enacted at both an interactional level and on a policy level. For example, a participant highlighted that one of the reasons that community mental health services are lacking is that it is widely believed that adults with serious mental illness are not capable of being productive members of a community and successfully engaging in various occupations. On an interactional level, a person is unlikely to believe claims of proficiency in occupations asserted by an individual with serious mental illness (Crocker & Lutsky, 1986; Goffman, 1963). For example, during a fieldwork day, a member shared that he had won a local Special Olympics tournament in basketball; however, I had difficulty in believing his claims. It was not until the member showed me the medal that I believed his claims. It was due to my stigmatizing notions about the member's proficiency in the sport of basketball (an occupation for the member) that I did not believe his claims. Indeed, Estroff (2018) accurately highlights that having a serious

mental illness is “like being on parole for your whole life,” as community members may not believe the claims of an adult with serious mental illness, an idea previously highlighted in stigma research (Crocker & Lutsky, 1986). Stigma is also maintained via social distancing and exclusionary practices, which, entail barring an individual with serious mental illness from participating in an occupation or a community activity (Corrigan et al., 2001; Martin & Pescosolido, 2015). For example, many adults with serious mental illness are excluded from participating in employment opportunities because they are assumed to be incapable of performing the job per expectations, which further limits opportunities for economic and social advancement (Draine et al., 2002; Krupa, Kirsh, Cockburn, & Gewurtz, 2009; Pugh et al., 2015). Further, it is adequately evidenced that occupations act as sites for building, enacting, and maintaining relationships (Dunbar & Roberts, 2006; Ulfseth, Josephsson, & Alsaker, 2015). In line with Goffman’s (1963) proposal that an analysis of relationships is required to understand stigma, studying relationships via occupational engagement provided the opportunity to understand processes that guide experiences of stigma. Thus, this dissertation highlights that stigma, a social force, is enacted via occupations, including community participation.

Further, this dissertation highlights that hierarchy is an integral aspect of both stigma and occupational engagement. In both the stigma and occupational science literature there is a lack of understanding regarding how social capital or position influence experiences of stigma and occupational engagement (Martin & Pescosolido, 2015; Prodinger et al., 2015; Thornicorft et al., 2007; Whiteford & Hocking, 2012). For example, while some scholars agree that social hierarchy or socio-economic status influence stigma, a systematic review found that no socio-economic demographic had an influence on internalized stigma (Abdullah & Brown, 2011; Corrigan & Watson, 2002; Link & Phelan, 2001; Livingston & Boyd, 2010; Pescosolido et al.,

2008; Oexle, Biol.Hum, & Corrigan, 2018). This study found that a person's place in the social hierarchy and their accumulated socio-economic capital affect his or her ability to adjust to or repel stigma. Further, in the field of occupational science, it is widely agreed that social hierarchy influences occupational engagement and that occupations are sites for enactment of social hierarchy (Angell, 2012; Cutchin et al., 2008; Galvaan, 2015; Nyman, Josephsson, & Isakkson, 2013). However, there is a lack of understanding regarding the social processes that constitute the relationship between social hierarchies and occupational engagement. Using the moral economics of occupations framework, which conceptualizes occupations as assets, this study situates social hierarchy at the center of occupational engagement in two ways: 1) an individual's social position or capital dictates one's agency to participate in an occupation and 2) exchanges of occupation determine one's ability to move within a social hierarchy and thus, maintains the social architecture of various institutions. For example, an executive director of a clubhouse has agency to participate in all occupations assigned to clubhouse culinary staff; however, a culinary staff cannot engage in all the occupations of an executive director. Culinary staff will have to demonstrate numerous capabilities and knowledge to be able to engage in the occupations available to an executive director. It is the specificity of capabilities and knowledge related to the occupations that helps maintain a hierarchy and thus, an institution itself.

Another important finding from this study was the influence of texts (such as intervention notes and policy documents) on occupational engagement and stigma towards mental illness. The importance of texts in shaping occupational engagement continues to be discussed within occupational science scholarship (Laliberte Rudman, 2005; Robinson & Bagatell, 2017). For instance: Laliberte Rudman (2005) highlighted the influence of texts (newspapers) in shaping expectations related to aging and the occupational engagement for older adults. This dissertation

highlights that texts not only shape occupational engagement but also preserve the institutions under which occupations are situated, a finding similar to past research (e.g., Robinson & Bagatell, 2017). For example, the way a weekly note or person-centered plan is created for a member not only helps a clubhouse get reimbursed, it also maintains the way psychosocial rehabilitation is planned to be by larger institutions, as highlighted in Chapter 4 (p. 57). Thus, due to the situated nature of occupations, texts shape both the current and future occupational engagement of individuals. Further, stigma is also maintained via texts. A plethora of evidence exists highlighting the role of media in sustaining stigma towards mental illness (Klin & Lemish, 2008; Wahl, 1997). This dissertation pushes the evidence forward by highlighting the influence of texts on stigma within mental healthcare. For example, during the fieldwork, when Nolan (member) found out that he could not access his own mental healthcare notes, he said, “this is not just. You should have access to your own history.” Another member, Melinda also shared Nolan’s frustration and said “oh, it’s a matter of trust.” Melinda elaborated that policy stakeholders may not trust consumers enough to allow them to have access to their own histories, as the (mental healthcare) system thinks that they are unreasonable or unfit to have such access. Melinda’s views were echoed by a policy expert who was reflecting on a change in policy to allow consumers who have been involuntarily committed to have access to their files:

She (a policy stakeholder) said we oppose this change (to allow consumers who have been involuntary committed access to their files) because essentially what she said was these are crazy people and we don't know if they get this information and they see who the petitioner was or they see who the doctor was they may get mad at them and then want to go kill them.

Thus, study findings demonstrate the influential role of texts in shaping experiences of occupational engagement and experiences of stigma.

Finally, this dissertation used social interactions to better understand occupational engagement and stigma towards mental illness. While social interactionism continues to be employed within scholarly fields like sociology and anthropology to examine various social constructs and processes, there are few studies that study interactions as an analytical unit to examine occupational engagement or stigma towards mental illness. As highlighted in earlier chapters, stigma continues to be fervently studied via a language of attributes using survey methodology and such practices have limited understanding of stigma (Estroff et al., 1991; Estroff et al., 2004; Thornicroft et al., 2007; Pescosolido & Martin, 2015). This dissertation provides evidence that occupations, stigma and institutions are not simply abstractions of cultural or systemic practices but are representations of individuals' interactions, behaviors, and relationships. With each interaction, an individual develops an understanding about self, others, and context (Angell, 2012; Bourdieu, 1998; Cutchin et al., 2008; Proding et al., 2015). For example, in this study, it was through an interaction that a member realized the kind of relationship he had with his family:

We recently attended my mother's funeral and before the funeral began the church had just the immediate family and Sharon (clubhouse staff). We were standing together, my brother and his partner, my younger brother and his wife. Sharon and I were at the same distance from any one of them. They made eye contact with and spoke with everybody there, including Sharon but did not include me in the conversation and only occasionally made eye contact with me. I was never asked a question. I would know that a comment or statement was directed at me but that entire time I was just basically invisible and ignored.

It is through the dynamics of the above interaction that this member learned about the pervasiveness of stigma in his family. The findings of this dissertation are an amalgamation of numerous such interactions and their role in guiding occupational engagement and stigma.

7.4 Implications for Occupational Science and Occupational Therapy

Much of the implications related to occupational science have been elaborated in Chapter 4. This section will provide a brief summary of the implication highlighted earlier and will expand on the implications of the findings on occupational therapy practice. This dissertation conceptualizes occupations as tangible assets to better understand the social process of occupational engagement. I do not suggest that we should abandon acknowledging the complexity of occupational engagement for the sake of conceptualizing occupational engagement via formulaic processes. However, conceptualizing occupations as assets provides insight into how occupations guide hierarchy and agency to maintain institutions, including the manifestation of macro level processes at the micro level. As highlighted in Chapter 4, such conceptualization helps in understanding the relationship between humans, occupations, agency, social capital, texts, and institutions.

Finally, this dissertation provides an example of how occupational science serves as a foundation for occupational therapy practice. Specifically, this dissertation highlights that community participation (an aspect of occupational engagement) is a key element in addressing stigma towards mental illness, as it is via successful community integration that ill-informed stereotypes regarding adults with serious mental illness can be challenged. As the research grows, contemporary mental healthcare is moving towards community-based care (Kane et al., 2015; Rosenhack et al., 2016). While mental healthcare was a significant part of occupational therapy's inception during the 19th century, unfortunately, research and practice in this area continues to decline (Gutman & Raphael-Greenfield, 2014; Peloquin, 1989). During 2010, only 3% of the total occupational therapy workforce was practicing in mental healthcare (AOTA, 2010). Current evidence indicates that occupational therapy can assist in community

participation of adults with serious mental illness (Brown & Stoffel, 2011; Bullock & Bannigan, 2011; Edgelow & Krupa, 2011; Gibson, D'Amico, Jaffe, & Abersman, 2011; Haertl, Behrens, Houtujec, Rue, & Ten Haken, 2009). Specifically, the client-centered approach used by occupational therapy can help devise specific interventions based on a client's identified needs that may pertain to community participation, instead of focusing simply on reduction in symptomatology (Gibson et al., 2011). Unlike various medical-focused models of care, occupational therapy interventions focus on life and community participation skills, which can have direct impact on clients' community participation and their ability to gain resources to maintain community participation (Bullock & Bannigan, 2011; Haertl et al., 2009). Further, occupational therapy's focus on the therapist-client relationship within a supportive therapeutic environment provides a context of care where clients can guide their own interventions, which can help reduce experiences of stigma within the mental healthcare system (Gahnström-Strandqvist, Josephsson, & Tham, 2004; Haertl et al., 2009). The underlying tenets of occupational therapy interventions, such as client-centered approach and client empowerment, also align well with the recovery movement heralded by individuals with serious mental illness (Anthony, 1993; Brown & Stoffel, 2011). Thus, given the unique focus of occupational therapy intervention on participation and client engagement, the intervention can help address community participation concerns of this population, effectively addressing stigma within various communities.

However, more research is required to assess occupational therapy's involvement and efficacy in contemporary community-based or psychosocial mental healthcare interventions, such as Assertive Community Treatment, the Individual Placement and Support model or the Clubhouse model. As the evidence regarding community mental healthcare emerges, it is timely

for the profession to reinvigorate the study of mental healthcare practices, in order to place the profession at the forefront of community mental healthcare. As occupational therapists continue to take on the role of practitioners and advocates, integration of occupational therapy within community mental healthcare will help reintegrate adults with serious mental illness into their communities and also assess occupational therapy's impact on addressing stigma in a community.

7.5 Implications for the Stigma Research

This study employed an ethnographic approach to study stigma towards mental illness and proposed the principle of gradient rationality as a guiding mechanism for stigma. An important implication of this research is a call for methodologically diverse research on stigma towards mental illness. As highlighted in earlier chapters, survey methodology is limited in its ability to provide sophisticated understandings of the social processes related to experiences of stigma (Estroff et al., 2004; Pescosolido & Martin, 2015; Thornicroft et al., 2007). Thus, more qualitative and mixed-methods research collecting perspectives from adults with serious mental illness and service-provider is required. Methodologically diverse studies are also required to unearth distinct social processes that guide experiences of stigma in distinct contexts, such as different countries. For example, since stigma is dependent on mental healthcare and knowledge regarding mental illness, social processes guiding stigma in the United States might differ from those in India or other countries (Bell et al., 2010; Jain & Jadhav, 2009; Manago, Pescosolido, & Olafsdottir, 2018). Evidence generated from diverse methods that appreciates the culturally situated nature of stigma will help generate culturally-informed interventions that can effectively address stigma in distinct communities (Manago et al., 2018; Napier et al., 2014; White &

Sashidharan, 2014). Thus, there is a need to employ diverse methodologies to better understand and address stigma.

Further, this dissertation argues that community participation, enabled by policy structures, is a key to dismantling stigma. Evidence suggests that social contact is an effective strategy; however, this dissertation argues that community members may categorize some individuals who are able to reintegrate back in communities as exceptions among those with mental illnesses. Thus, in the absence of policy changes that address structural stigma and assist in community reintegration of adults with serious mental illness, social contact may not have long-term influence in addressing stigma. Stigmatizing attitudes are deeply held beliefs that are sustained via the interplay of structural stigma and marginalizing policies (Angermeyer, Matschinger, Link, & Schomerus, 2014; Corrigan et al., 2005; Pescosolido et al., 2008; Pugh et al., 2015). In order to challenge stigmatizing attitudes, a concerted effort to assist adults with serious mental illness achieve successful community (re)integration is required. Thus, studies evaluating policies and their influence on community participation along with studies that help examine and address stigma among policy-makers are required.

7.6 Theoretical Support

This dissertation is informed by the knowledge generated by Pierre Bourdieu, Dr. B. R. Ambedkar, and Michel Foucault. I employed Bourdieu's (1998) ideas of habitus and social capital to strengthen findings related to hierarchy and occupational engagement. As discussed in the previous chapters, Bourdieu highlighted that an individual's social position impacts his/her rationalities for actions, and thus, occupational engagement (Cutchin et al., 2008). Ideas related to hierarchy and stigma were strengthened via ideas of social hierarchy laid out by Dr. B. R.

Ambedkar, an Indian scholar²⁵. Ambedkar highlighted that, in a social hierarchy, the most integral class is the one that represents the lowest category, every other class exists only in relation to the lowest class. Regarding social hierarchy within the Indian caste system, Ambedkar (1989) argued, “there is no such class as a completely unprivileged class except the one which is at the base of the social pyramid. The privileges of the rest are graded. Even the low is privileged as compared with lower” (p. 101-2) Ambedkar’s ideas are central to the principle of gradient rationality, which highlights the implications of social hierarchy for stigma, when coupled with the ideas from Foucault (1965). Foucault’s ideas related to the perceived unreason of mental illness helped conceptualize unreasonableness as a core component of defining and stigmatizing mental illness. Being reasonable or of sound mind is an integral component for defining a human. However, similar to Ambedkar’s ideas, Foucault highlighted that it is unreason that represents the lowest limit of human reason and is one of the determining factors for stigma towards mental illness. Ultimately, reason exists only in opposition to unreason, as Foucault (1965) highlighted: “to respect madness is not to interpret it as the involuntary and inevitable accident of disease, but to recognize this lower limit of human truth, a limit not accidental but essential, as death is the limit of life” (p.81). It was through the ideas of these influential scholars that I was able to conceptualize the ideas I have provided in this dissertation.

7.7 Conclusion

Adults with serious mental illness continue to experience stigma, both on an interactional and on a structural/institutional level, as a significant barrier to community participation, an integral aspect of occupational engagement. In order to better understand the relationship between the social processes related to stigma and occupational engagement, this dissertation

²⁵ Ideas outlined by Ambedkar were identified during the early stages of data analysis, and thus, were not part of the initial theoretical framework used to design the study.

proposes three distinct yet connected social processes (stigma on an interactional and policy level is enacted via dynamics of occupational engagement). This dissertation provides a conceptual framework to better understand the social process of occupational engagement by conceptualizing occupations as tangible assets. The findings also describe how stigma functions on an interactional level and its connection to stigma at the structural/institutional level. Future research is required to assess the validity and applicability of the proposed frameworks in different settings. Future research regarding marginalizing policies is also required in order to address structural/institutional stigma, as many adults with serious mental illness continue to struggle due to systemic issues, such as incarceration, unemployment, poverty, and homelessness (Draine et al., 2002; Pugh et al., 2015).

In the United States, the history of mental illness is, among other things, an account of individuals with serious mental illness experiencing discrimination, alienation, and institutionalization (Grob, 1994; Torrey, 1997). There have been periods where reasonable care was provided to the population; but, those periods were, often, followed by disconcerted strategies that were not always beneficial for individuals with serious mental illness (Grob, 1991; Grob & Goldman, 2006). Further, the past and current hardships of adults with serious mental illness are not by chance, and also, cannot be entirely attributed to their symptomatology. As evidenced in the literature and illustrated by this dissertation, a significant factor affecting the social maltreatment of this population is stigma towards mental illness (Pugh et al., 2015, Thornicroft et al., 2009; Torrey, 2011; Pescosolido & Martin, 2015). Thus, this dissertation is primarily an attempt to reinvigorate the scientific examination of stigma towards mental illness and its impact on community participation, in order to provide better life opportunities for adults with serious mental illness.

APPENDIX A: INFORMED CONSENT FORMS

SERVICE-USER

University of North Carolina at Chapel Hill

Consent to Participate in a Research Study

Adult Participants

Consent Form Version Date: __01/16/2017__

IRB Study # 16-2920

Title of Study: An ethnographic analysis of stigma toward mental illness and mental health care at Clubhouses in North Carolina.

Principal Investigator: Nikhil Tomar

Principal Investigator Department: Allied Health Sciences

Principal Investigator Phone number: 414-364-5659

Principal Investigator Email Address: nikhil_tomar@med.unc.edu

Faculty Advisor: Antoine Bailliard

Faculty Advisor Contact Information: 919-966-8188; antoine_bailliard@med.unc.edu

What are some general things you should know about research studies?

You are being asked to take part in a research study. To join the study is voluntary.

You may refuse to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study.

You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

What is the purpose of this study?

The primary purpose of this study is to identify experiences related to stigma and engagement in mental health care for individuals with mental illness.

Are there any reasons you should not be in this study?

Consider participating only if you are 18 years old or older, have a diagnosis of psychotic (such as schizophrenia) or mood disorders (such as depression), and can communicate in English. You are not eligible for the study if you have current or previous experience within the past six months of accessing or utilizing care for comorbid diagnosis of substance abuse or a developmental disorder/disability such as cerebral palsy.

How many people will take part in this study?

I hope to recruit 20-30 individuals with mental illness accessing services at a clubhouse.

How long will your part in this study last?

The study will be conducted for approximately 6 months, January – June 2017. However, you do not have to participate in the study for the entire period and can *withdraw* from the study at any time.

What will happen if you take part in the study?

Participation in this research study will include engaging in an interview (1-2 hours to completion) and allowing the primary investigator to observe your daily activities at the clubhouse. Interviews will be audio-recorded after gaining permission from a participant. You will also be requested to complete a survey measure regarding your participation in the community. Please note the primary investigator will be participating at the clubhouse only 2-3 days per week during the study period.

Additionally, if you choose to provide consent, your health care records will be accessed to document your past and present health care information.

What are the possible benefits from being in this study?

The study will provide insight regarding service-users' engagement in mental health care and their interactions with service-providers at a clubhouse. Such insights may benefit the mental health care services provided at a clubhouse and may provide future guidance to modify institutional policies, in the context of mental health care at a clubhouse.

What are the possible risks or discomforts involved from being in this study?

Due to potential sensitivity toward the issue of mental illness, participants (service-users) may experience some emotional distress during interview. It is noted that the distress experienced during an interview might not exceed that of a typical conversation with one's peers or friends or family members. However, you can quit the interview, participant observation or the study at any point, without any penalty. Further, if you feel any discomfort you can contact staff at the clubhouse or your service-provider at any point of the interview.

Other risks include breach of confidentiality and loss of reputation via information obtained through the consent form. However, participants pseudonyms will be used to record data and the raw data will not be shared with any one not included as research personnel for the project

How will information about you be protected?

To help protect your confidentiality, the interview and field note data will be collected only using participant pseudonym and your real name will not be used. Further, physical copies of your consent forms and demographic data will be stored in a locked cabinet accessible only to the primary investigator and will not be shared with anyone who is not listed as research personnel in this project. Furthermore, all electronic data (such as audio recordings) collected during the study will be stored in password protected computers accessible only to research personnel listed in this project. Audio-recording will be transcribed during or after the data collection and destroyed after the data has been analyzed.

What if you want to stop before your part in the study is complete?

If you decide to withdraw from the research study before it ends, you may do so without any penalty or influence on your role as a service-user at the clubhouse. However, information collected up to that point will be used for research purposes.

Will you receive anything for being in this study?

Participants will not receive any incentive for participating in this study.

Will it cost you anything to be in this study?

No, there is no cost to participate in the survey.

What if you are a UNC student?

Participation in this research study, or the lack thereof, will in no way influence your standing as a student or university employee.

What if you have questions about this study?

You have the right to ask, and have answered, any questions you may have about this research. If you have questions about the study (including payments), complaints, concerns, or if a research-related injury occurs, you should contact the researchers listed on the first page of this form.

What if you have questions about your rights as a research participant?

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject, or if you would like to obtain information or offer input, you may contact the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Your participation in this research is voluntary, and you will not be penalized or lose benefits if you refuse to participate or decide to stop.

Signing this document means that the research study, including the above information, has been described to you orally, and that you voluntarily agree to participate.

Name and Signature of participant

Date

Signature of investigator

Date

INFORMED CONSENT FORM (SERVICE-PROVIDER)

University of North Carolina at Chapel Hill

Consent to Participate in a Research Study

Adult Participants

Consent Form Version Date: ____11/10/2016____

IRB Study # 16-2920

Title of Study: An ethnographic analysis of stigma towards mental illness and mental health care at Clubhouses in North Carolina.

Principal Investigator: Nikhil Tomar

Principal Investigator Department: Allied Health Sciences

Principal Investigator Phone number: 414-364-5659

Principal Investigator Email Address: nikhil_tomar@med.unc.edu

Faculty Advisor: Antoine Bailliard

Faculty Advisor Contact Information: 919-966-8188; antoine_bailliard@med.unc.edu

What are some general things you should know about research studies?

You are being asked to take part in a research study. To join the study is voluntary.

You may refuse to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study.

You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

What is the purpose of this study?

Primary purpose of this study is to identify the social processes guiding experiences of stigma and mental health care for individuals with mental illness.

Are there any reasons you should not be in this study?

Consider participating only if you are 18 years old or older and have provided mental health care services at the clubhouse during past 6months.

How many people will take part in this study?

In terms of participating in the study, I hope to recruit n=5-10 staff members or mental health care service providers working at a clubhouse.

How long will your part in this study last?

The study will be conducted for approximately 6months, January – June 2017. However, a participant do not have to engage in the study for the entire period and can *withdraw* from the study at any time.

What will happen if you take part in the study?

Participation in this research study will include engaging in an interview (1-2hours to completion) and allowing the primary investigator to participate with you to observe your daily activities at the clubhouse. Please note the primary investigator will be participating at the clubhouse only 2-3days per week during the study period.

What are the possible benefits from being in this study?

This study will provide evidence regarding social processes guiding engagement in mental health care and factors influencing service-user/service-provider interactions at a clubhouse. This evidence will benefit the mental health care services provided at a clubhouse and highlight future guidance to modify institutional policies, in the context of mental health care at a clubhouse.

What are the possible risks or discomforts involved from being in this study?

As the interview data and field notes (constructed on the basis of participant observation) will be collected using pseudonyms and will not be shared with anyone who is not an investigator on the project, information provided by service providers and their views will be confidential and will not affect their career prospective. Therefore, there is minimal risk for participation in this study for service-providers.

How will information about you be protected?

To help protect your confidentiality, the interview and field note data will be collected only using participant pseudonym and your real name will not be used. Further, physical copies of your consent forms and demographic data will be stored in a locked cabinet accessible only to the primary investigator and will not be shared with anyone who is not listed as research personnel in this project. Furthermore, all electronic data collected will be stored in a password protected computers accessible only to research personnel listed in this project.

What if you want to stop before your part in the study is complete?

If you decide to withdraw from the research study before it ends, you may do so without any penalty or influence on your role as a service-provide at the clubhouse. However, information collected up to that point will be used for research purposes.

Will you receive anything for being in this study?

Participants will not receive any incentive for participating in this study.

Will it cost you anything to be in this study?

No, there is no cost to participate in the survey.

What if you are a UNC student?

Participation in this research study, or the lack thereof, will in no way influence your standing as a student or university employee.

What if you have questions about this study?

You have the right to ask, and have answered, any questions you may have about this research. If you have questions about the study (including payments), complaints, concerns, or if a research-related injury occurs, you should contact the researchers listed on the first page of this form.

What if you have questions about your rights as a research participant?

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject, or if you would like to obtain information or offer input, you may contact the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Your participation in this research is voluntary, and you will not be penalized or lose benefits if you refuse to participate or decide to stop.

Signing this document means that the research study, including the above information, has been described to you orally, and that you voluntarily agree to participate.

Signature of participant

Date

Signature of investigator

Date

INFORMED CONSENT FORM (POLICY EXPERTS OR STAKEHOLDERS)

University of North Carolina at Chapel Hill

Consent to Participate in a Research Study

Adult Participants

Consent Form Version Date: ____01/16/2017____

IRB Study # 16-2920

Title of Study: An ethnographic analysis of stigma toward mental illness and mental health care at Clubhouses in North Carolina.

Principal Investigator: Nikhil Tomar

Principal Investigator Department: Allied Health Sciences

Principal Investigator Phone number: 414-364-5659

Principal Investigator Email Address: nikhil_tomar@med.unc.edu

Faculty Advisor: Antoine Bailliard

Faculty Advisor Contact Information: 919-966-8188; antoine_bailliard@med.unc.edu

What are some general things you should know about research studies?

You are being asked to take part in a research study. To join the study is voluntary.

You may refuse to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study.

You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

What is the purpose of this study?

Primary purpose of this study is to identify the social processes guiding experiences of stigma and mental health care for individuals with mental illness.

Are there any reasons you should not be in this study?

Consider participating only if you are 18 years old or older and are involved in studying or informing mental healthcare policies to assist or work with a clubhouse OR have worked/assisted a clubhouse during past 6months.

How many people will take part in this study?

I hope to recruit 4-8 individuals engaged with mental health care policies to assist/work with a clubhouse.

How long will your part in this study last?

The study will be conducted for approximately 6 months, January – June 2017. However, as a participant, you will have to conduct only one interview and do not have to participate in the study for the entire period and can *withdraw* from the study at any time.

What will happen if you take part in the study?

Participation in this research study will include engaging in an interview (1-2 hours to completion). Interviews will be audio-recorded after obtaining participant's permission.

What are the possible benefits from being in this study?

This study will provide evidence regarding social processes guiding engagement in mental health care and factors influencing service-user/service-provider interactions at a clubhouse. This evidence may benefit the mental health care services provided at a clubhouse and may highlight future guidance to modify institutional policies, in the context of mental health care at a clubhouse.

What are the possible risks or discomforts involved from being in this study?

As the interview data will be collected using pseudonyms and will not be shared with any one who is not an investigator on the project, information provided by you and your views will be confidential and will not affect your career prospective. Therefore, there is minimal risk for participation in this study for service-providers.

How will information about you be protected?

To help protect your confidentiality, the interview and field note data will be collected only using participant pseudonym and your real name will not be used. Further, physical copies of your consent forms and demographic data will be stored in a locked cabinet accessible only to the primary investigator and will not be shared with anyone who is not listed as research personnel in this project. Furthermore, all electronic data collected will be stored in password protected computers accessible only to research personnel listed in this project.

What if you want to stop before your part in the study is complete?

If you decide to withdraw from the research study or the interview before it ends, you may do so without any penalty or influence on your role.

Will you receive anything for being in this study?

Participants will not receive any incentive for participating in this study.

Will it cost you anything to be in this study?

No, there is no cost to participate in the survey.

What if you have questions about this study?

You have the right to ask, and have answered, any questions you may have about this research. If you have questions about the study complaints, concerns, or if a research-related injury occurs, you should contact the researchers listed on the first page of this form.

What if you have questions about your rights as a research participant?

All research on human volunteers is reviewed by a committee that works to protect your rights

and welfare. If you have questions or concerns about your rights as a research subject, or if you would like to obtain information or offer input, you may contact the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Your participation in this research is voluntary, and you will not be penalized or lose benefits if you refuse to participate or decide to stop.

Signing this document means that the research study, including the above information, has been described to you orally, and that you voluntarily agree to participate.

Signature of participant

Date

Signature of investigator

Date

APPENDIX B: CONSENT FORM TO RELEASE MEDICAL INFORMATION

University of North Carolina at Chapel Hill

Consent to Participate in a Research Study

Adult Participants

Consent Form Version Date: ____11/10/2016____

IRB Study # 16-2920

Title of Study: An ethnographic analysis of stigma toward mental illness and mental health care at Clubhouses in North Carolina.

Principal Investigator: Nikhil Tomar

Principal Investigator Department: Allied Health Sciences

Principal Investigator Phone number: 414-364-5659

Principal Investigator Email Address: nikhil_tomar@med.unc.edu

Faculty Advisor: Antoine Bailliard

Faculty Advisor Contact Information: 919-966-8188; antoine_bailliard@med.unc.edu

1. PATIENT IDENTIFICATION SECTION

1.1. Name: _____

1.2. Date of Birth: _____

2. WRITTEN CONSENT

2.1. I, _____, hereby consent to the release of the following information from my medical records to Nikhil Tomar

2.2. Specific Information: Mental health care records available at the clubhouse and/or to the clubhouse staff.

This written consent is subject to revocation at any time by writing or verbally communicating to the health care provider or the clubhouse staff who is to release the information. I understand that this information will be used only for research purposes and will never be shared with any other person or entity. If shared, for research purposes, the information will be shared only among investigators of this project and using a pseudonym and without any name and date of birth information.

I also understand that raw information from my records will never be shared for any research reporting or dissemination.

I also understand that to revoke this consent, I can simply sign and date the revocation section of this form and deliver it to the health care provider or the clubhouse staff.

This consent has been fully explained to me and I understand its contents

_____ (Signature of the service-user)

_____ (Date)

3. REVOCATION SECTION:

I hereby revoke release of any of my Mental health care records to Nikhil Tomar

_____ (Signature of the service-user/family member)

_____ (Date)

4. CONSENT EXPIRATION

This consent will expire 6 months after the date when it was obtained.

5. IRB CONTACT INFORMATION

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject, or if you would like to obtain information or offer input, you may contact the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

APPENDIX C: INTERVIEW GUIDE

Interview Guide (Consumers)

Demographical data:

1. Participant ID (Pseudonym): _____
2. Age: years
3. Sex: _____ (0=Male 1=Female)
4. Highest Level of education
 - a. No education
 - b. Elementary education (till 5th grade)
 - c. Finished high school
 - d. Some College
 - e. Bachelors degree
 - f. Masters degree
5. Location of interview:
 - a. Home
 - b. Facility
 - c. Other: _____
6. Employment status
 - a. Full time
 - b. Part time
 - c. Salaried employment
 - d. Daily wages worker
 - e. Self-employed
 - f. Unemployed
 - g. Retired
 - h. Other: _____
7. Marital status
 - a. Married
 - b. Separated
 - c. Divorced
 - d. Widowed

- e. Single, never married.
 - f. Other: _____
8. Living situation
- a. Living alone
 - b. With parents
 - c. With significant other
 - d. Other: _____
9. Family members you remain in contact with:
- a. Mother
 - b. Father
 - c. Brother
 - d. Sister
10. Clinical diagnosis: _____
11. Duration of illness: _____
- a. 6months-1year
 - b. 1-2 years
 - c. 2-5years
 - d. >5years
12. Frequency at the clubhouse: _____days/week
13. What is caregiver's main occupational status?
- _____
14. What is caregiver's CURRENT employment status?
- a. Self-employed
 - b. Full- time employment
 - c. Part-time employment
 - d. Not employed

Interview questions

- How did you find out about this place?
 - Or how were you referred to this place?
 - Do you come here regularly? Why or why not?

- What does your usual day looks like?
- What do you know about your diagnosis?
- What do you think people around you (your family, friends, community members staff at the clubhouse, etc) think about you?
- What do you think community members think about this place
 - Can you give any example of your interactions with community members?
- How do you feel about being at the clubhouse?
 - How do you feel about about the staff and their work?
- What do you think can make your experience at the clubhouse better?
- Would you mind drawing a lifeline regarding significant events of your life?
- Would you mind drawing a simple line diagram of your social network?

Stigma

- What do you think stigma towards mental illness looks like?
- Why do you think such stigma exists?
- Have you ever felt stigmatized in the community?
 - Can you give any example?
 - What about your experiences at the clubhouse? Have you ever felt stigmatized here?
 - Can you give any example?

Community participation

- What does your participation in the community looks like?
- Are others willing to participate with you in the community?
 - Follow-up: why do you think that is the case?
 - Any examples?
- Do you think you contribute to your family or community in any ways?
- What factors do you think hinders your social participation?
- What has been your overall experience with the care you have received for your health problem?
 - How about your relationship with your healthcare provider?

- Anything you would like to add or tell me more about your social participation?

Medications

- What do you think about taking medications?
- How do you feel when you take medications?
- Are they of any help?
- In any context, do you tell people that you take any medications?
 - Yes or no: why?
- Why do you think these medications are given to you?
- Do you intend to continue taking the prescribed medications life long?
- Anything you would like to add or tell me more about medications?

Interview Guide (Service providers)

Demographical data:

1. Age
 - a. 18-24
 - b. 25-34
 - c. 35-44
 - d. 45-54
 - e. 55 or above
2. Gender: _____
3. Number of years at the clubhouse:
 - a. 1-3years
 - b. 4-6years
 - c. 6-9 years
 - d. >10years
4. Contact Information: _____

Interview Questions

- What does your usual day at the clubhouse looks like?
- How many consumers do you provide care?
- What are some of the challenges to your job?

- What do you think about stigma in MH policies, especially the ones that pertain to the clubhouse?
 - How do these policies influence your interactions with members?
- How or why did you become a service-provider at the clubhouse?
- Do you think stigma interferes with members' participation in community or at the clubhouse?
 - How and why?
 - What do you think can be done to address this issue?
 - Do you think service providers can help decrease stigma in a community? How and why?
 - Because of being a mental health care provider, have you experienced any stigma and/or discrimination from community members?
- Do members raise concern about social participation in the community?
 - What are some of those concerns?
 - Why do you think those concerns exist?

Interview Guide (Policy experts/stakeholders)

Demographical data:

1. Participant ID: _____
2. Age
 - a. 16-24
 - b. 25-34
 - c. 35-44
 - d. 45-54
 - e. 55 or above
3. Gender: _____
4. Number of years at the clubhouse:
 - a. 1-3years
 - b. 4-6years
 - c. 6-9 years
 - d. >10years

5. Contact Information: _____

Interview Questions

- For how long have you been working with or studying mental healthcare policies?
- How would you describe mental healthcare policies at the state level?
- How would you describe mental healthcare policies at the federal level?
- How do you think these policies influence member-staff interactions at a clubhouse
- What are some of the challenges for having ideal mental healthcare policies? Ideal here means what you think ideal policies can be.
- What do you think about stigma in mental healthcare policies?
 - How do these policies influence the clubhouses?
 - How does the stigma embedded in policies influence interactions between members and staff at a clubhouse?
- How do you think stigma embedded in mental healthcare policies influence members' participation in a community or at a clubhouse?

APPENDIX D: OBSERVATION GUIDE

- What is the social geography of the place of interaction?
 - How are the physical objects (chair, tables, etc.) placed?
 - What spaces do the participant/s occupy? (e.g.: sitting at the end of the table)
- What are the physical (body) expressions of the participants during the interaction? (e.g.: loud speech, heavy breathing etc.)
- How often does a participant speak in the interaction?
- How many people are engaged in the interaction and what are their roles?
- How long did the interaction last?
- Did any participants have any strong emotional reaction during the interaction? What were the reasons for such emotional response?
- What was the major theme of interaction?
- What were some of the factors that influenced the interaction (lack of attention from member or staff)?

APPENDIX E: PRELIMINARY CODE BOOK

1. Perspectives on stigma
 - a. What is stigma?
 - b. Experiences of stigma
 - i. Within the context of mental healthcare
 - ii. In the community
 - c. Perspectives on stigma at an interactional level
 - d. Strategies to address stigma
2. Perspectives on participation in the clubhouse
 - a. Daily routines or usual participation
 - b. Perspectives on staff-member interactions
 - i. Perspectives on hierarchy
 - c. Experiences on being a member
 - d. Concerns or challenges related to membership engagement
 - e. Benefits of participation in the clubhouse model
3. Perspectives or concerns related to community participation
 - a. Involvement in advocacy
 - b. Resources available for community participation
 - i. Influence of limited resources on community participation
 - c. Influence of policies on community participation
 - d. Influence of stigma on community participation
4. Perspectives on mental healthcare policies
 - a. Role or influence of stigma on mental healthcare policies

- b. Challenges related to mental healthcare policy decision-making
- c. Influence of mental healthcare policies on clubhouse participation
- d. Perspectives on consumer advocacy in mental healthcare policy decision-making

APPENDIX F: FLYER

If you are interested in the study or have any question, feel free to call Nikhil Tomar (Graduate Student) at 414-364-5659 or email at: nikhil_tomar@med.unc.edu

Nikhil Tomar nikhil_tomar@med.unc.edu 414-364-5659
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Nikhil Tomar nikhil_tomar@med.unc.edu 414-364-5659

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