

TOWSON UNIVERSITY  
COLLEGE OF GRADUATE STUDIES AND RESEARCH

MEDICATION ADHERENCE, SOCIAL SUPPORT, AND RECOVERY:  
PERSPECTIVES OF INDIVIDUALS WITH SCHIZOPHRENIA SPECTRUM  
DISORDERS AND THEIR FAMILIES

By

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A dissertation in partial fulfillment of the requirements for the degree of  
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## ABSTRACT

### Medication Adherence, Social Support, and Recovery: Perspectives of Individuals with Schizophrenia Spectrum Disorders and their Families

Susan D. Krutis

Medication non-adherence for individuals with schizophrenia spectrum disorders is a problem with serious consequences to personal health, family relationships, and the community at large. Occupational therapists in mental health facilitate medication management strategies and need to be informed in order to determine best practice approaches. This study utilized a qualitative multiple case-study approach to examine the lived experiences of four consumers and four families relative to psychiatric medication adherence, social support, and recovery. In-depth, semi-structured interviews and brief recovery surveys were completed. Results suggest that consumers in this study incorporated medications as a process that illustrated development of self-awareness. Consumers' desire for greater autonomy in early adulthood emerged as a powerful influence on their sense of liminality. Parents articulated that medications were necessary for their adult children's illnesses, and that decisions about how to support their adult children were complicated. The findings of this study have important implications for occupational therapists in the delivery of client-centered mental health care to support individuals and their families with medication adherence.

**KEY WORDS:** medication adherence, social support, recovery, schizophrenia, occupational therapy

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## CHAPTER 1: INTRODUCTION

Living with schizophrenia gives rise to a number of demands and challenges to daily life. One of the most common battles individuals face is that of regularly taking psychiatric medications, prescribed for the purpose of managing distressing symptoms such as psychosis. Formerly referred to as compliance and more recently adherence, this problem vastly impacts the person with illness, family members, friends, and society at large (Gray, Robson, & Bressington, 2002; Gray, Wykes, & Gournay, 2002; Seale, Chaplin, Lelliot, & Quirk, 2006). In short, the problem is severe enough to emotionally shatter lives, generating intense burden for all who are affected (Bebbington, 1995; Fenton, Blyer, & Heinssen, 1997; Lefley, 1996).

Recurrent psychosis that results from medication non-adherence not only leads to multiple hospitalizations, but can potentially lead to homelessness, violence, suicide, and incarceration (Bebbington, 1995; Estroff, Zimmer, Lachicotte, & Benoit, 1994; Lefley, 1997; Reyers, 2010; Velligan et al., 2009; Zygmunt et al., 2002). Devastating personal, familial, and socioeconomic effects of schizophrenia and non-adherence have led the World Health Organization to establish research as a key priority (WHO, 2003). Although research has resulted in mixed reviews relative to interventions for this problem, medication adherence rates have not changed in at least four decades (Kikkert et al., 2006; Zygmunt et al., 2002).

This chapter will begin with an introduction to a building line of research inquiry. In this section, the reader will first become acquainted with the researcher's initial clinical observations that eventually led to a salient research inquiry relative to

individuals' and families' experiences with psychiatric medications. This will also provide a glimpse into a need for occupational therapy to enter into this important conversation about medication adherence, in the opinion of this researcher, and to consider whether current professional frameworks are sufficient to address this problem in practice. The chapter will continue with a description of the problem statement, potential contributions of the study, research questions, definitions of relevant terms, limitations of the study, and the purpose statement.

### **Background**

This multiple case research study about medication adherence for individuals with schizophrenia and their families essentially grew from my anecdotal clinical experiences as an occupational therapist, working on a research unit with individuals diagnosed with schizophrenia. These clinical experiences led to an overarching question about what may constitute best practice for occupational therapists to facilitate adherence to medications.

Medication management is considered within the scope of practice for occupational therapy, identified as an instrumental activity of daily living (AOTA, 2008). Typical interventions for problems with medication management used by occupational therapists may include adaptive and restorative approaches centering on improvement of underlying cognitive capacities.

One example of this type of approach may be to utilize an alarm watch as a memory aid for taking medications on time. Another intervention, as used by this clinician, is the utilization of clinical programs that focus on medication management skills. Known as the Independent Medication Program in my clinical work, programs

such as these can provide opportunities for individuals to practice recall of medication properties such as dosage, purpose, or side effects. In addition, individuals who participate may be asked to approach the nurse to request medications at scheduled times.

It was during the course of participation in the Independent Medication Program that many individuals made profound statements about their feelings relative to medications, and at times even provided glimpses of their intentions to stop taking medications. During clinical interactions, it became obvious that these very individuals, when a trusting relationship was present, seemed to want and need to talk about their experiences surrounding medications. The incredible complexity of the struggle to take, or not to take medications, became apparent in comments such as “I don’t understand how sleeping more equals better function” or “am I myself when I take medications?”

Adherence was not recognized as an original aim of this medication program, particularly since asking for medications in the hospital did not appear to necessarily equate to adhering to medications once in the home environment. However, these windows of opportunity for straightforward conversation about medications emerged in the course of this skill-based program.

This was seen as a welcome occurrence, but one in which occupational therapy was called to consider first how to react to the harsh truth of non-adherence, and then to contemplate how to proceed with intervention. Or even whether occupational therapists’ scope of practice supported intervention for this problem? After all, the psychiatrist and nurses have an obvious role in medication prescription and education.

While medication management skills have long been viewed within the scope of practice for occupational therapists (AOTA, 2008), less understood are strategies that address underlying motivational capacities of individuals to follow, or adhere to their medication regimens. Occupational therapists are concerned with helping individuals to engage in lives of meaning, participating to their fullest capacity in communities of choice (AOTA). Therefore, a focus on individuals' adherence to the medications, which theoretically enable better function through symptom reduction, appears to be of relevance to the profession.

The clarity of occupational therapy's role in medication adherence does not appear to be well-established beyond skill-based interventions used for medication management. Certainly, facilitating cognitive and organizational skills to manage daily medication routines can be viewed as important to daily life. However, the desire to take medications, or lack thereof, would seem to be a significant prerequisite to skill development. In short, organizing the pill box will not do much good if the individual does not intend to open it.

Indeed, medication adherence cannot be packaged neatly into a formal medication program. Then again, not much about human beings can be precisely understood in a simplistic, linear way. This is also the case for individuals with schizophrenia who live with the consequences of a chronic condition each day they wake up, and every night when they go to bed.

Occupational therapy, under a biopsychosocial approach, considers a complex range of issues related to biological, emotional, and interpersonal characteristics that

interfere with performance of meaningful activities (Cara & MacRae, 2005). Further, a role for occupational therapy has been to engage individuals in the rebuilding of meaningful life while living with a chronic health condition. The complexities of life with a severe and persistent mental illness provide an important context for an equally complicated problem. That is, the decisions of individuals with schizophrenia to comply, or not, with the recommendations of their physicians in terms of taking psychiatric medications, usually for the remainder of their lives.

### **The Research Problem**

*“No pill can help me deal with the problem of not wanting to take pills”* (Jamison, 1995, p. 89).

### **Individuals with Schizophrenia: Medication Adherence**

It is estimated that upwards of 50-75% of individuals with schizophrenia will become non-adherent to psychiatric medications within the first two years of treatment (Gray, Robson, & Bressington, 2002; Lieberman et al., 2005; Roe et al., 2009). Since antipsychotic treatment is the first line of defense as an intervention for a disease believed to originate biologically (Hirsch & Weinberger, 2003), non-adherence is of particular significance.

This is especially the case now, as studies on genetics and brain anatomy are in the scientific forefront, in what researchers hope will lead to better treatments and an ultimate cure for schizophrenia (Hirsch & Weinberger, 2003; Shean, 2004; Torrey, 2006). As psychiatry has enveloped the medical model of care, similar in many ways to the treatment of physical diseases such as cancer, pharmacological interventions hold a position of importance in mental health care delivery (Torrey, 2006).

These pharmacological treatments are prescribed in the context of an influential health care delivery system driven by the medical model (Bebbington, 1995). This paradigm places the prescriber in the driver's seat, therefore emphasizing an asymmetrical relationship between prescriber and patient. In essence, patients are expected to "comply" with medication protocols based on the premise that physicians know what is best for the person (Bebbington). Hence, paradigm shifts have called for changes in terminology from compliance to adherence or concordance in order to reduce the perception of blame toward the patient (Gray, Robson, & Bressington, 2002; Gray, Wykes, & Gournay, 2002; Seale et al., 2006).

However, the medical model remains a socially sanctioned presence in health care today, not just in the case of physicians but many providers of health care such as occupational therapists (Bebbington, 2005; Mattingly & Fleming, 1994). In general, individuals who do not adhere to medication regimens are frowned upon by providers who function according to medical model paradigms. Occupational therapists, for example, have focused clinical and research efforts toward their patients' adherence to splint wearing, use of adaptive equipment, and home exercise programs (Radomski, 2011).

Beyond these consequences, literature consistently points to grave consequences that result from medication non-adherence such as recurrent hospitalizations, more frequent and intense relapse of psychosis, increased suicide risk, decreased quality of life, and increased risk for aggression or violence against others (Bebbington, 1995; Donohoe et al., 2001; Fenton, Blyer, & Heinssen, 1997; Hamer, 2006; Velligan et al., 2009). In addition, individuals who do not adhere to medication regimens have been shown to have

poorer outcomes (Bebbington; Velligan et al.). Therefore, serious consequences to personal, social and economic systems make this an important area for study.

Notably, a potential contribution to outcome for medication adherence may also be the stage in which individuals seek their first treatment (Hirsch & Weinberger, 2003). The first treatment connection is typically not made until approximately one year after onset of initial symptoms. The duration of untreated psychosis (DUP) has been linked, although not with certainty, to an unfavorable course of illness (Hirsch & Weinberger).

Some researchers believe that beginning antipsychotic treatment early in the illness course may help to improve chances of a favorable response, thereby improving odds for better function (Hirsch & Weinberger, 2003; Reyers, 2010). It has been a difficult problem to study because many individuals have vague signs of illness onset (Hirsch & Weinberger). However, a new research study funded by the National Institute of Mental Health (NIMH) seeks to study this very issue by providing proactive early intervention to individuals who have had a recent initial episode of psychosis, for the purpose of improving rates of recovery (Reyers). So, it may be even more important to study individuals in the earlier phases of illness, which we already know tend toward high rates of non-adherence as early as the first two years of treatment (Gray, Robson, & Bressington, 2002; Lieberman et al., 2005; Roe et al., 2009).

Individuals with schizophrenia have difficulty with adherence to psychiatric medications for a variety of reasons. It may be of surprise to realize, however, that they are not alone in the struggle as adherence rates are similar to those with other chronic illnesses such as diabetes, asthma, arthritis, and high blood pressure (Marland & Cash,

2005; Rogers et al., 1998). Factors involved in the decision of individuals with schizophrenia to adhere to medications have included features of the person's illness, social environmental influences in the medical community and from the public at large, economic environmental impacts, and properties of antipsychotic medications (Velligan et al., 2009; Weiden, 2007). Occupational therapists may view these components in terms of person, environment, and occupation (Law et al., 1996).

For example, person related characteristics that have been cited in the literature thus far have included severity and persistence of illness symptoms, inferior cognitive capacities, poorer insight into the mental illness, and the extent to which individuals believe medications are efficacious to managing symptoms (Bebbington, 1995; Velligan et al., 2009). Social environmental influences have mainly focused on inferior relationships and alliances between individuals and prescribers, lack of family support, and the stigma brought forth by society relative to mental illness and symbols of psychiatric medication use (Lefley, 1996; Velligan et al.). A large number of studies point to negative influences of family members, particularly when families are considered to have a more critical or hostile approach, known as "high expressed emotion (EE)" in their interactions with a relative who is mentally ill (Hirsch & Weinberger, 2003; Lefley, 1996; Tarrier & Barrowclough, 1990; Velligan et al.).

Another commonly cited factor in non-adherence is the cost of antipsychotic medications, a thorny issue for individuals who have likely "drifted down" toward poverty levels (Hirsch & Weinberger, 2003; Velligan et al., 2009). Then, there is the important issue of side effects that individuals endure from antipsychotic medication use such as excessive fatigue, cognitive dulling, extrapyramidal symptoms, sexual

dysfunction, and weight gain (Bunn et al., 1997; Hirsch & Weinberger, 2003).

Complaints relative to side effects of medications are still apparent in the literature, even after the introduction of newer generation medications that are said to be more effective with less negative effects (Shean, 2004).

Although a number of these factors repetitively appear in copious quantitative research studies, it is not entirely known as to the degree of impact each has relative to medication adherence (Velligan et al., 2009). By and large, review of the literature on medication adherence leads to an awareness of the remaining ambiguity regarding the problem. Some of the more commonly cited factors by researchers are insight, belief in efficacy of medication, alliances with providers, and severity of psychotic symptoms (Bebbington, 1995; Donohoe et al., 2001; Hamer, 2006; Patterson et al., 2002; Velligan et al.).

However, little replication of studies in this field and use of various quantitative research designs and hypotheses have contributed to the sense of uncertainty about what contributes to adherence problems, and more importantly, how to solve them (Velligan et al., 2009; Weiden, 2007). In reality, medication adherence likely results from a variety of multi-layered phenomena, because there appears to be a combination of personal, environmental, and medication characteristics involved in the decision making process (Roe et al., 2009; Velligan et al.; Weiden).

A few qualitative studies in the mental health field have provided rich descriptions of issues related to medication adherence in individuals with chronic mental health conditions, including processes involved in deciding to stop medications (Roe et

al., 2009) and the impact of medication on self-identity (Karp, 2006). These types of studies support the complexity of this issue, illustrating the non-linear and dynamic characteristics inherent to a very human struggle. However, much remains to be explored about medication adherence. Using qualitative methods may permit the complexity to further emerge, informing the ways in which the problem is viewed. Furthermore, this knowledge will hopefully contribute to shaping novel interventions that will lead to positive outcomes.

### **Conceptual models: Understanding adherence**

A number of theories have been utilized by researchers in the field to shed light on the problem of medication adherence, including the Health Belief Model (HBM) and Cognitive Behavioral Therapy (CBT). The HBM began as a preventive model but later expanded to explain the health decision-making process. This model highlights ways in which individuals may weigh costs versus benefits of accepting treatment as incentives for health (Bebbington, 1995; Becker, 1985; Budd, Hughes, & Smith, 1996; Rosenstock, Strecher, & Becker, 1988). CBT operates on the notion that individual beliefs and assumptions are based on faulty cognitive thought processes and schemas, and that perceptions of experiences are the *polarizing filter* (Dattilio & Freeman, 1992; Meichenbaum, 1995; Turkington, Dudley, Warman, & Beck, 2004).

However, using these models to explain complex health decision processes in application to schizophrenia has been criticized based on the premise of symptoms such as thought disorder and decreased insight into illness (Bebbington, 1995). Critics point to the possibilities of delusional or false beliefs, rather than a true psychological denial of illness or need for treatment (Bebbington). Furthermore, some argue that individuals

with schizophrenia may not have the cognitive ability to self-assess and change thought processes, and that their beliefs are often influenced by an intricate delusional system (Bebbington).

Information gained from each of these models, such as self-efficacy, motivation, and incentives for health, are important features to consider in this study. However, one cannot deny the presence of symptoms unique to schizophrenia spectrum disorders such as delusional beliefs, decreased insight into illness, and interruptions in thought processes. It is primarily for this reason that this researcher has journeyed elsewhere in terms of theoretical models to guide analysis of processes related to medication adherence for this population.

What largely drew this researcher to the recovery model is the undeniable focus on the broader context of life lived with severe mental illness. In the context of recovery, it is impossible to argue whether individuals with schizophrenia fit the bill. Recovery, in essence, claims to have been written by and for individuals who live with chronic mental illnesses. If the model has a core assumption, it would be that individuals have the right to break out of sick roles and move forward with their lives (Anthony, 1993; Davidson et al., 2009).

Another model, Person-Environment-Occupation (PEO), originating within the occupational therapy profession, was chosen to highlight the layers and levels of complexity involved in carrying out occupations (Law, 1996). Transactional relationships among person, environment, and the occupation components occur in dynamic ways to create the actual performance of an occupation (Law et al.). As the

literature alludes to, researchers interested in studying this topic need to consider a variety of influences within person, environment, and occupation categories that impact medication adherence.

### **Recovery and Medication Adherence**

Recovery in mental illness has become more of a focus in health care delivery systems as a result of increasing research from perspectives of consumers, as well as from a policy and legislative standpoint (Deegan, 2005; Davidson & Roe, 2007; Lieberman et al., 2008; Mead & Copeland, 2000). As research began to surface about what it means to recover from chronic mental illness, the model of recovery began to take shape, becoming more visible in the 1990's (Anthony, 1993; Deegan, 2005; Mead & Copeland). Although a number of informative qualitative studies have been accomplished, along with development of research instruments targeting recovery, lack of a concise definition continues to besiege its noble principle (Anthony; Davidson & Roe; Jacobson & Greenley, 2005; Lieberman et al.; Ng et al., 2008).

As such, recovery has been defined in a number of ways (Jacobson & Greenley, 2005; Lieberman et al., 2008), and has been referred to using an assortment of terms inclusive of “an approach, a model, a vision, a movement, or even a myth” (Ng et al., 2008, p. 119). The U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA) set forth a consensus statement on mental health recovery, which includes ten fundamental components: a) self-direction, b) individualized and person-centered, c) empowerment, d) holistic, e) non-linear, f) strengths-based, g) peer support, h) respect, i) responsibility, and j) hope (<http://mentalhealth.samhsa.gov>). The consensus statement also incorporates concepts of

healing as a journey and the enablement of meaningful life. This statement resonates with core principles of occupational therapy as participation in meaningful life activities is a primary objective (AOTA, 2008).

The essence of recovery is that individuals have the right to move forward with their lives with hope, even if symptoms remain and the illness is not resolved, or cured (Anthony, 1993; Davidson & Roe, 2007; Deegan, 2005; Jacobson & Greenley, 2001; Lieberman et al., 2008; Lysaker & Buck, 2006). This paradigm stands in opposition to the traditional medical model where biological interventions are prioritized as expert providers predict the unrelenting course of schizophrenia (Ng et al., 2008). One of its strongest arguments is that at least half of individuals with mental illness actually get better rather than worse over the course of their illness (Bellack, 2006; Carpentier, 2006; Davidson et al., 2009). Furthermore, recovery is described as a dynamic process in the life of the individual with severe mental illness (Corrigan, 2006; Davidson et al.; Lieberman et al.).

Recovery has also been described as a social process, unfolding not only in individual experiences, but through social relationships with others (Hendryx, Green, & Perrin, 2009; Schon, Denhov, & Tapor, 2009; Tapor, Borg, DiGirolamo, & Davidson, 2009). As individuals move forward in their recovery, other people such as friends, families, and professionals are significant influences. So, recovery is advanced with the support of other people, inclusive of good relationships and alliances (Tapor et al.). However, little is known about what constitutes the establishment of good relationships that would seem to support recovery (Breier & Strauss, 1984; Tapor et al.).

In addition, little is understood about how medication adherence relates to recovery for individuals with schizophrenia (Ng et al., 2008; Noordsy et al., 2000; Roe et al., 2009). Ng et al. (2008) found that participants believed they could not be in recovery until they stopped medication and were able to resume steady work. Roe et al. (2009) suggested that non-adherence decisions were based on a multi-step process inclusive of complex personal dilemmas, conflicts and struggles about the decision, resolving of the issue, and development of personal perspectives about medication that supported non-adherence. Much remains to be discovered related to the problem of medication adherence, including how consumers may view medications within the process of their own recovery.

### **Families as Social Support: Medication Adherence**

Families are most often a critical social link for individuals with schizophrenia (Jungbauer & Angermeyer, 2002; Lefley, 1998). Following deinstitutionalization, families have become even more crucial to support their relatives with mental illness as they attempt to live their lives in the community versus psychiatric hospitals (Lefley, 1998). Historically, they have been portrayed in a negative light in terms of their influences on relapse rates and adherence to medications. They have been blamed as contributors to consumers' negative opinions of medications (Santone et al, 2008), in addition to the provision of hostile home environments that lack warmth and lead to over-involvement, as suggested by research on expressed emotion (Jungbauer et al., 2004; Pyne et al., 2006; Sellwood, TARRIER, Quinn, & Barrowclough, 2003).

Because many people with schizophrenia live at home and are dependent upon their families for support, family members likely have a significant influence in

medication adherence (Brady & McCain, 2004; Bebbington, 1995). As highlighted previously, family members are also a part of the recovery process for individuals with mental illness (Hendryx, Green, & Perrin, 2009; Schon, Denhov, & Tapor, 2009; Tapor et al., 2009).

Although the family has been implicated as a part of recovery, little is known about dimensions of this role or the impact of the recovery movement on the family (Glynn, Cohen, Dixon, & Niv, 2006). For example, the recovery movement emphasizes the consumer's desire for autonomy, but a poignant question is whether or not families are willing to be led by consumers (Glynn et al.). This, of course, also brings to light the problem of medication non-adherence, and how features of recovery such as empowerment and autonomy may impact individual and family systems for the better, or perhaps for the worse.

Also less understood and lacking in current literature, are the ways in which family members may provide physical and emotional support for relatives' medication adherence (Carpentier, 2006; Lefley, 1996). Literature on caregiver burden provides a useful backdrop of life with relatives who are chronically mentally ill, and is considered informative to the issue of support. However, few studies address the specific issues related to medication adherence and support, beyond the occasional review of dilemmas involving covert delivery of medications in foods or beverages (Wong, Poon, & Hui, 2005).

In terms of caregiver burden, medication non-adherence has certainly contributed to disruption of family routines and relationships (Brady & McCain, 2004; Jungbauer &

Angermeyer, 2002; Koukia & Madianos, 2005; Lefley, 1997; Lefley, 1996; Rudge & Morse, 2004; Tuck, du Mont, Evans, & Shupe, 1997). Research has revealed that families anticipate psychosis if they are aware of a non-adherence episode (Lefley, 1996). Families may also attempt to search for ways to maintain homeostasis, avoiding verbal conflicts so as not to invite trouble or cause a family commotion (Rose, 1998). In fact, sharing a household with a relative who is mentally ill is related to particularly intense burden as families try to manage the daily challenges associated with the illness (Gallagher & Mechanic, 1996; Walton, Gerson, & Rose, 2005). It is not difficult to imagine the overwhelming experience families endure behind closed doors.

Because most individuals are diagnosed between the ages of 17 and 25 (Torrey, 2006), illness in the early adulthood phase of life poses significant difficulties for the achievement of developmental milestones such as greater autonomy and financial independence (Carter & McGoldrick, 2005). Individuals in this phase of life, therefore, have an atypical need for support by their parents and other family members, which can lead them to endure intense feelings of inadequacy (Lefley, 1997). This can lead to displaced anger bestowed on families by consumers who symbolize families as the source of their suffering (Lefley, 1997).

The experience of illness for the individual goes on to affect the entire family system (Rolland, 2005). In this way, both individuals and families embarking on the illness journey endure significant challenges. It is not unusual for families to have difficulty separating from their adult children with mental illness, and to become enmeshed in response to the intense needs that are set in motion by the illness process (Carpentier, 2006; Chrzastowski, 2007; Jungbauer et al., 2004). So it seems that social

support for family members with chronic mental illnesses introduces a set of new demands based on a theme of dependence rather than autonomy.

Although literature is scarce on the topic of social support, one helpful study by Breier & Strauss (1984) used qualitative methods to determine consumers' perceptions of important features in social relationships. Consumers with psychotic mental illnesses described characteristics that were deemed to be fundamental to supportive social relationships. These included features such as the ability to ventilate or converse with other people and to experience social approval instead of being ostracized for their illness. In addition, consumers revealed that social supports offered an opportunity for problem-solving situations and to provide insight into themselves.

Another useful research study by Rose (1998) examined reciprocal relationships that contribute symbolically to meanings associated with care giving. Using qualitative methodology, care givers revealed three themes, which included: a) the family's search for ways to stay connected with the ill member, b) ways the family influences the ill member with words, actions, and presence, and c) ways that family helped the ill member to move forward, whether that involved "stepping back" or "stepping in" (p. 367).

This brings forth thoughts about social support that are applicable to this study. If social approval or problem-solving are seen as helpful aspects of social relationships by individuals with mental illness (Breier & Strauss, 1984), it would be apt to consider the applicability of these ideas of support, and other emerging influences relative to medication adherence. Also serving to inform the issue of medication adherence is the examination of how family members stay emotionally connected (Rose, 1998) relative to

concerns over medications. Or, when given a glimpse of intent to stop medications, do they more likely ignore the problem in an effort for peace in the home, albeit temporary?

Social support may also refer to how families may use words, actions, or mere presence (Rose, 1998) to communicate values and beliefs about psychiatric medication use, or non-use. In terms of medication adherence, one wonders how family members may use strategies that are analogous to stepping back or stepping in (Rose). And, furthermore, how do these strategies help or hinder medication adherence?

### **Summary of the Problem**

The multi-faceted problem of non-adherence for individuals with schizophrenia and their families is one that is not easily solved. If it were straightforward, adherence rates may have been improved in past years (Bellack, 2006). Thus far, research surrounding adherence is largely quantitative, with little understanding about the layers of phenomena that envelop the decisions of so many to become non-adherent to their psychiatric medications.

For consumers and families alike, subjective definitions of adherence relative to living life with mental illness are a worthwhile direction of study. When compared to the number of quantitative research studies available on medication adherence, the subjective experiences of individuals and families are lacking. Furthermore, consumer and family visions of social support and recovery may impact medication adherence in complex ways that have yet to be discovered. Again, the gap in literature has not yet permitted an in-depth view of how these dimensions may interact to affect this vast problem. This provides a strong foundation in terms of need for this study.

### Potential Contributions to Occupational Therapy

Occupational therapy supports the value of engagement in occupations and the considerable connection occupations have with the health and well-being of individuals (Christiansen, 1999; Reilly, 1961; Peloquin, 2002). According to PEO, occupations are defined as “clusters of activities and tasks in which the person engages in order to meet his or her intrinsic needs for self-maintenance, expression, and fulfillment” (Law et al., 1996, p.16). The profession acknowledges that occupations are wrought with deeper meaning, although they may appear to be simple and ordinary (Christiansen, Baum, & Bass-Haugen, 2005). In addition, occupations are symbolically connected to the social world, and as such, harvest meaning in ways that are multifaceted (Christiansen, Baum, & Bass-Haugen).

The roots of the occupational therapy profession are based upon theories of doing. Consider Mary Reilly’s (1961) famous quote: “That man, through the use of his hands, as they are energized by mind and will, can influence the state of his own health.” A simple act of doing, in the context of powerful underlying meanings, can influence the abilities of individuals to get well and remain well. But, in the case of non-adherence to medications, what hypotheses can be generated by occupational therapists when individuals seem to choose *not doing* or *undoing*?

Available research studies have consistently pointed to the fact that not taking medications can lead to ill effects in health (Bebbington, 1995; Gray, Wykes, & Gournay, 2002; Kikkert et al., 2006; Lefley, 1997). Also, it is known that individuals with schizophrenia struggle with the performance of many other occupations in areas of self-

care, leisure, sleep, and productive life (Cara & MacRae, 2005). It is possible, too, that *not doing* also influences the state of personal health, albeit negatively.

But, is there something important that occupational therapists and other mental health providers are missing in the quest to help individuals with their medications? If individuals with schizophrenia are going to stop taking their medications, and many do; are efforts toward education and “skills” in vain? If so, it would be the case that programs that primarily emphasize skill building or compensation may be missing the boat entirely. In essence, occupational therapists and other providers may be placing a band-aid on a wound that runs much deeper.

As occupational therapists partner with consumers to help them rebuild lives of meaning, it is pertinent to consider how they view their own recovery processes. Individuals’ definitions of recovery in real-life may differ significantly from scientific definitions (Bellack, 2006; Jenkins & Carpenter-Song, 2005). Their visions of recovery may also impact their views on medication as a continual presence in their lives (Jenkins & Carpenter-Song; Ng et al., 2008; Roe et al., 2009).

Furthermore, occupational therapy should possess a firm grasp of the role of family supports in the process of recovery. They too may differ from consumers’ visions, which may impact the ability of families to effectively help consumers with managing their illness (Glynn, Cohen, Dixon, & Niv, 2006). Conversely, consumers may not be able to receive the support they desire. Should similarities in visions for recovery surface, aspects that are helpful to medication adherence may also come to light.

Families are involved in the recovery process for consumers, serving key roles in their lives (Glynn et al., 2006; Schon, Denhov, & Topor, 2009). Since the illness is diagnosed in late adolescence and early adulthood, individuals and their families endure many hardships in the process of not only accepting the illness, but living with it every day (Lefley, 1996). Understanding social supports involved in medication adherence, while moving beyond the focus of family as a contributor to relapse, will serve to inform best practices in mental health care for individuals and families. In addition, occupational therapy as an interdisciplinary team member could play a role in facilitating early interventions that may be important in better preparing individuals and their families to manage their illness.

The purpose of research in this field is to inform health care practices (Cara & MacRae, 2005). Research is also the means by which occupational therapy will remain a reimbursable service by third party payers (Ottenbacher, Johnson, & Hojem, 1988). Therefore, clinical research methods that support delivery of best practice health care should continually be developed and utilized in the profession. As Ottenbacher et al. (1988) propose, traditional scientific approaches may not be sufficient to capture the data needed in order to meet the demands of the clinical world. The case study design is suggested as a method to document clinical changes, but cannot be used to demonstrate cause and effect relationships.

Research is an important recommendation in the occupational therapy profession, primarily to record evidence of our treatment methods and to continue development of theories that support the importance of our work with individuals (Cara & MaCrae,

2005). Evidence-based research studies are encouraged in order to test best practice interventions in terms of outcome.

For this study, it is fitting to first engage in exploratory research in order to determine subjective influences involved in medication adherence, and to attempt to generate explanations that may fit or rival occupational therapy's scope of practice and theoretical foundation. Only after influences are understood can occupational therapists truly develop their roles in clinical practice. And only then can subsequent evidence-based studies be used to determine best practice methods in the area of medication adherence. As Yerxa strongly suggests, occupational therapists should refrain from roles as biomedical technicians, but instead transform into detectives in search of novel ideas that contribute to the profession and to humankind (Cara & MaCrae, 2005).

Qualitative research methods using case study research, although not large scale fit the need for investigating phenomenon related to medication adherence from the perspectives of those who live with mental illness each day. Certainly, attempts at understanding adherence in the context of a larger process such as recovery calls for a methodology that is capable of encapsulating this depth. Qualitative methods allow the researcher to gain perspectives of multiple layers of a problem from participants (Creswell, 2003). This approach will be used to explore underlying complex processes of medication adherence, social support and recovery as described by consumers and families in this study (Creswell).

Finally, occupational therapy theories, in their emphasis on doing, may or may not support the issues relevant to individuals who encounter this serious problem of

medication non-adherence. Currently, dimensions and relationships must first be discovered within complex layers of person, environment, and occupation components before a common language can develop or supplement occupational therapy models of theory and practice.

### **Research Questions**

The focus of this research study was the phenomenon of medication adherence, foremost for consumers with schizophrenia who constitute the primary case. The experience of families was a secondary focus of this study, serving to provide perspectives about consumers that informed analysis of the issue. Three key concepts were considered for both individuals and families including medication adherence, social support, and recovery. The following research questions were considered for consumers and families:

#### Consumers

1. How do consumers with schizophrenia experience medication adherence?
2. How do consumers experience social support by families surrounding medication adherence?
3. Do consumers view medication adherence as part of their recovery processes; and if so, how?

#### Families

1. How do family members view experiences with medication adherence?
2. How do family members define their social support role relative to consumers' medication adherence?
3. Do family members view medication adherence as part of consumers' recovery processes; and if so, how?

## Definition of Terms

This section will define concepts pertinent to the study, including concepts that are referred to within theoretical frameworks of PEO and recovery.

*Schizophrenia Spectrum Disorders* refers to the diagnosis of schizophrenia (paranoid, disorganized, residual, or undifferentiated types) or schizoaffective disorder by a psychiatrist who utilized criteria set forth in DSM-IV TR.

*Occupational therapy* is a health care profession that provides clinical services inclusive of evaluation and interventions, with the overarching goal of supporting health and participation in life through engagement in occupations (AOTA, 2008).

*Engagement in occupation* is defined as “the commitment made to performance in occupations as the result of choice, motivation, and meaning and includes objective and subjective aspects of carrying out activities meaningful and purposeful to the individual person, organization, or population” (AOTA, 2008).

*Medication adherence* is the occupation in question for this study, referring to the consumer’s ability to regularly follow prescribed medication regimens. Though the primary self-care occupation of medication adherence is the focus of this study, it is assumed that this occupation is nested within other meaningful occupations in life, and that it is closely connected to the social world (Christiansen, Baum, & Bass-Haugen, 2005).

*Continuum of adherence* refers to the notion that medication adherence is rarely an all or nothing principle (Donohoe et al., 2001; Hamer, 2006; Patterson et al., 2002; Velligan et al., 2009). Therefore, a spectrum of adherence is assumed for this study. On one

extreme, consumers may decide to completely stop medications. On the other extreme, consumers may be pondering the possibility of altering or stopping medications. Or, the pattern of adherence may fall anywhere in between.

*Medication Management* is defined as an instrumental activity of daily living (AOTA, 2008) inclusive of a complex combination of skills required for performing tasks related to taking medication.

*Individuals/Consumers* refer to persons living with schizophrenia spectrum disorders. At times, when discussing the context of family relationships, they may also be referred to as relatives.

*Key family members* are defined as relatives through biology or by adoption who are closely associated with a family member who has the mental illness of schizophrenia. A broad criterion inclusive of immediate to extended family members is set for this study, as a variety of types of families may be involved in supporting the person with illness. Examples include, but are not limited to: parents, spouses, siblings, grandparents, aunts, uncles, or cousins. The most likely supports for the individuals in the early adulthood phase of life are parents.

*Early adulthood* refers to the general age range of 21-35 years based on Carter and McGoldrick's Expanded Family Life Cycle model (2005). Typical developmental milestones associated with this age group include autonomy, career development, separation from families of origin, emergence of close relationships with partners, marriage, and raising young children. Individuals who are diagnosed with schizophrenia

in early adulthood are limited with achievement of developmental milestones that are typically realized during this phase of life.

*Social support* is defined as the ways that individuals with illness are helped, both practically and emotionally, by other people. Social support may constitute words, actions, and presence (Rose, 1998). Although social supports could be inclusive of many types of relationships including friendships, this study specifically focuses on family members as social supports.

*Person-Environment-Occupation (PEO): Person* is defined as one of three important components within the transactional relationship with environment and occupation. The person is composed of mind, body, and spirit and is influenced by life experiences that have shaped who he is, inclusive of his personality, competencies, self-concept, and culture. People change developmentally through the life span, and are motivated and always changing while performing occupations and interacting with the environment (Law et al.).

*Person-Environment-Occupation (PEO): Environment* is also part of the transactional relationship with person and occupation. Broadly defined in PEO, environment includes cultural, socio-economic, institutional, physical, and social components. The environment impacts behavior in the sense that contexts contain cues that influence human response (Law et al., 1996; Rigby & Letts, 2003).

*Person-Environment-Occupation (PEO): Occupation* refers to “clusters of activities and tasks in which the person engages in order to meet his or her intrinsic needs for self-maintenance, expression, and fulfillment” (Law et al., 1996, p.16).

*Person-Environment-Occupation (PEO): Occupational performance* is defined as the outcome of transaction between person, environment, and occupation components (Law et al., 1996).

*Fit and lack of fit* refer to the extent of overlap between the interaction of person, environment, and occupation components. This affects the outcome of occupational performance as components either work more or less compatibly with one another. When the overlap is closer, the outcome is a better fit. Conversely, when less overlap occurs, the outcome is less fit.

*Recovery*, both an outcome and a process, is largely defined as encompassing components of hope, empowerment, self-agency, and resilience. Recovery emphasizes the rights of individuals with illness to move forward with life, pursue goals, follow dreams, and manage their health (Corrigan, 2006; Davidson et al., 2009; Deegan, 2005; Lieberman et al., 2008; Noh, Choe, & Yang, 2008). Recovery has also been defined as a social process (Borg & Davidson, 2008).

*Recovery from mental illness* refers to a cure for mental illness, or a cessation of symptoms associated with the illness (Davidson & Roe, 2007).

*Recovery in mental illness* refers to how individuals continue to live life with illness despite residual symptoms of illness. In recovery, the person with illness is the agent of his or her own life (Davidson & Roe, 2007).

### **Limitations of the Study**

This study confined itself to the exploration of phenomena within experiences of medication adherence, mainly for consumers who live with schizophrenia. Family

members were a secondary focus, and provided perspectives that permitted elaboration relative to issues that plagued the consumer regarding adherence. Therefore, families were not viewed as the primary case in question for this particular study, mainly because this study on social support, recovery, and medication adherence is largely uncharted territory. Future studies with families as a primary focus may emerge as a result of this study.

Consumer-family dyads were considered, though observations of family and consumer in terms of relating with one another were limited since this research used private interviews (and not observational ethnography). Rather, examples of ways that families support the person with illness were an objective for analysis.

This study took place in the community versus the hospital setting. It was thought that the experience of medication adherence could be best understood by individuals who are living in the community, away from the structured environment of a hospital. Though an advantage to researching in this capacity is the lack of personal familiarity with participants and ability to immerse oneself into a researcher role, it can also be seen as a limiting factor in that access to information that builds an understanding of the case is more restricted.

This study was limited to four consumers and four accompanying family members. Due to the low number of participants and the nature of qualitative research, generalizability was not an objective of this study beyond comparison of patterns and differences across cases. The main focus of this study was bounded to examination of phenomena related to medication adherence, social support, and recovery (Yin, 2009).

### **Purpose of Study**

The purpose of this study was to describe the experience of psychiatric medication adherence from the perspectives of four consumers with schizophrenia spectrum disorders and four key family members who serve as social supports. In addition, this study sought to explore how medication experiences could be embedded within the context of personal and familial viewpoints of mental health recovery. Transcribed interviews and recovery questionnaires from multiple case studies were subjected to descriptive analysis within and across multiple cases.

### **Summary**

This chapter provided an introduction to the problem of medication adherence for individuals with schizophrenia and their families. Occupational therapy can add to the conversation about this devastating problem through expertise in analyzing complex transactional relationships among person, environment, and occupation components. In addition, the backdrop of life lived with mental illness, brought to light through elements of the recovery model, could provide a rich context from which to understand the experience of psychiatric medication adherence. This multiple case study aims to understand medication experiences of consumers who are living with this severe mental illness and their families who serve in social support roles within mental health recovery processes.

## CHAPTER 2: LITERATURE REVIEW

A thorough review of relevant research databases was completed in order to gather knowledge for the proposed study about experiences related to medication adherence, social support, and recovery for individuals with schizophrenia and their families. This chapter will provide an in-depth overview of topic areas that are pertinent to this study including: 1) psychiatric diagnoses of schizophrenia spectrum disorders, 2) medication adherence for individuals with schizophrenia, 3) families of individuals with schizophrenia, 4) Person-Environment-Occupation Model (PEO), 5) recovery model for mental illness, 6) integration of PEO and recovery, and 7) an overview of multiple case study methodology. The chapter will conclude with a brief summary of the literature review.

### **Schizophrenia Spectrum Disorders**

*“There once was a big place in our hearts for my son, filled with laughter, brightness, and mischief. Now he stands mute, eyes of pain asking if we have abandoned him. We haven’t really, but he seems like a bottomless pit that remains empty no matter how much love we pour into him. And we are left drained”* (Wasow, 1995, p. 1).

The diagnosis of schizophrenia is not often welcomed in the lives of those touched by it. Although it is now widely accepted as a brain disease, it is certainly far from the understanding, acceptance, and treatment of other physically based diseases (Torrey, 2006). Schizophrenia is considered to be a severe and persistent mental illness; characteristically chronic throughout one’s life (Hirsch & Weinberger, 2003; Torrey). As Torrey remarks, even the utterance of the word *schizophrenia* invokes intense visions of

bizarre madness. In essence, the brain is affected in such a way that it begins to play tricks in the form of voices, disorganized thoughts, and false beliefs (Torrey).

Those who bear this illness have therefore lost control of their brains, and are no longer the same in biological terms (Torrey, 2006). In this sense, it is hard to imagine a worse fate. Unlike many other physical illnesses, the person afflicted with schizophrenia will not die directly from the disease. But, for families, a son or daughter who lives with schizophrenia has lost his or her “being” in every other sense of the word, their former self appearing to vanish into thin air.

### **Diagnosis and Symptoms**

Schizophrenia, though certainly not a straightforward diagnostic process, is characterized primarily by the presence of bizarre delusions and/or auditory hallucinations (DSM-IV-TR, 2000). Secondly, the diagnosis depends on the presence of two or more symptoms in the categories of other delusions, other hallucinations, disorganized speech, disorganized or catatonic behavior, and/or negative symptoms (DSM-IV-TR). The illness tends to be episodic and prone to symptom exacerbations, even while regularly taking antipsychotic medication (Hirsch & Weinberger).

Schizoaffective disorder, according to DSM-IV-TR (2000), is characterized by recurring episodes of elevated or depressed mood along with psychosis. Acceptance of schizoaffective disorder as a diagnosis within the schizophrenia spectrum disorders is divisive, and some speculate that the subsequent version of the DSM will re-categorize this illness (Torrey, 2006). One reason for this could be the similarities between schizoaffective disorder and bipolar disorder, also known as manic-depressive illness

(Torrey). At any rate, schizoaffective disorder currently involves the predominance of mood dysfunction rather than thought disorders that are a hallmark of schizophrenia (Torrey).

Schizophrenia is also sub-typed by describing the presence of *positive* and *negative* symptoms (Torrey, 2006). Positive symptoms are defined as those symptoms that are present, but would typically be absent in persons without mental illness (Torrey). Examples of positive symptoms include delusions, hallucinations, and thought disorders. On the contrary, negative symptoms are those symptoms which are absent, but should be present (Torrey). Examples of negative symptoms that could occur with schizophrenia are apathy, blunting of emotions, decreased energy and drive, lack of pleasure from activities, poverty of thought, or social withdrawal.

Although delusions and hallucinations are not always present in schizophrenia, they are symptoms one is typically familiar with since they can manifest themselves in the form of bizarre or strange behaviors (Torrey, 2006). Delusions can take on many forms, but are generally considered to be false beliefs that the person misinterprets as reality (Torrey).

Paranoid type delusions, for example, can be observed when a person believes that officials in the government are seeking him or her in order to harm him or her. Delusions that are grandiose may center on the person's sense of importance, such as the belief that one is an important messenger of God or carrying out an important project for the government that nobody else is qualified to do. Some delusions are capable of

becoming quite threatening to safety, such as what may happen when one believes in the ability to fly, stop bullets, or when feeling persecuted by others (Torrey, 2006).

As illogical as delusional thoughts can appear, the sensory information is perceived as very real to the person with illness (Torrey, 2006). It is possible that a person experiencing delusional thoughts will be searching for clues in the environment to support their beliefs (Torrey). For example, believing that a family member is deceitfully planning his or her demise, the person misinterprets an innocent phone conversation as proof of the plan.

Because the person is so convinced that the delusion is real, it is usually not helpful for others to argue or reason away the false thinking (Torrey, 2006). The person who is experiencing the delusion is too involved with the convoluted thought patterns to have this ability (Torrey). Sometimes the delusional thinking will be fixed and therefore, difficult to reason with. Other times, however, persons may be ambivalent about their delusional thoughts which can cause confusion for families and professionals alike (Torrey).

Hallucinations are similar to delusions in terms of variability in types and intensity. Common hallucinations include auditory and visual, and less frequently olfactory, tactile, and taste (Torrey, 2006). Individuals who experience hallucinations may do so continuously without much pause or occasionally. Auditory hallucinations or “voices” are sometimes demanding, demeaning, or commanding in a negative sense, which contributes to the daily torture that many endure with this illness (Torrey, 2006).

Rarely, hallucinations can also be positive, pleasant, or utopist in nature (Hirsch & Weinberger, 2003; Torrey).

In addition to bizarre sensory experiences such as delusions and hallucinations, individuals also experience changes in thought processes (Hirsch & Weinberger, 2003; Torrey, 2006). Thought disorders are typically present in schizophrenia, though degrees and types of impairments are highly variable. Thought disorders include aspects of negative and positive symptoms, and are more accurately disorders of language versus cognition decline (Hirsch & Weinberger).

Examples of thought disorders include derailment, concrete thinking, incoherence, neologisms, poverty of speech, loose association, and illogicality (Hirsch & Weinberger, 2003). Thought disorders based on positive symptoms would include derailment or neologisms while those based on negative symptoms would include examples such as poverty of speech (Hirsch & Weinberger).

In addition to the presence of thought disorders, individuals with schizophrenia also experience a number of disturbances in emotion or feelings (Hirsch & Weinberger, 2003). One of the most difficult negative emotional symptoms to manage is *anhedonia*, or the loss of feeling and pleasure associated with activities one used to enjoy. This may manifest in lack of participation in activities, or in its social form, avoidance of being with friends or other people (Hirsch & Weinberger). Other examples of emotional disturbances include changes in affect (inappropriate or flat/blunted), depression, elation, and anxiety.

In addition, one of the most troubling emotional issues is that of *apathy*, or impaired drive in life. Notably, apathy is particularly difficult for family or caregivers as it has the potential to cause frustration and burden (Hirsch & Weinberger, 2003).

Imagine the aggravation this may cause for parents who desire nothing more than success and achievement in the life of their adult child, only to observe the manifestations of a stolen will to experience life.

Lastly, cognitive deficits are also common expressions in the illness of schizophrenia (Hirsch & Weinberger, 2003). Prominent features of cognitive impairment include attention span, shift in focus, intellectual pursuits (digit span, picture arrangement), judgment, memory, and perception. Notably, individuals with schizophrenia perform markedly worse on tests of intelligence when comparing pre-psychotic and full-blown illness states (Hirsch & Weinberger).

### **Prevalence**

Schizophrenia, renamed by Eugen Bleuler in 1911 from the previous Kraepelin term “dementia praecox,” is now somewhat accepted to include a spectrum of disorders inclusive of groupings of types of psychoses, moods, and personalities (Shean, 2004). However, research targeting specific brain chemistry tends to focus on the narrower concept of schizophrenia with core symptoms (Shean).

Because definitions of schizophrenia vary significantly, it is difficult to determine exact prevalence and incidence rates (Hirsch & Weinberger, 2003; Shean, 2004). An estimated one to four per 10,000 individuals in the world population is at risk per year to develop schizophrenia (Shean). That is, approximately 1% of the world population is

affected by schizophrenia (Hirsch & Weinberger; Opolka, Rascati, Brown, & Gibson, 2003; Torrey, 2006; Buckley, 2008). This is merely an estimate and does not include those who are indirectly affected, such as the countless numbers of families and caregivers who live with someone diagnosed with schizophrenia (Amador, 2007).

The onset of schizophrenia typically occurs in late adolescence and early adulthood years (Buckley, 2008; Hirsch & Weinberger, 2003; Torrey, 2006). Rarely, schizophrenia can also occur in childhood or late in adulthood (Hirsch & Weinberger; Torrey). In general, symptoms that may be noticeable early on in the illness may include depression, withdrawal, low energy, confused or bizarre thinking, suspiciousness, changes in self-care or hygiene, changes in sleep and eating patterns, hearing voices, or changes in school performance (Torrey, 2006). However, because the onset can also occur abruptly, seemingly without precursors, it is possible that little to no warning signs are present before a full blown psychotic episode (Torrey).

A gender effect has been noted in that males seem to be more commonly affected with the illness, and experience onset approximately 3-5 years earlier than females (Buckley, 2008; Shean, 2004; Torrey, 2006). For unknown reasons, males also tend to experience greater severity of symptoms, including cognition, and have poorer outcomes than females (Hirsch & Weinberger, 2003; Shean; Torrey).

Three quarters of those diagnosed with schizophrenia in this country are between the ages of 17-25 years (Torrey, 2006). For males and females alike, the early adulthood life cycle is particularly unique and, in a sense, fragile as children begin to form larger boundaries in their relationships with parents (Carter & McGoldrick, 2005).

Studies have also demonstrated a disproportionately high prevalence of schizophrenia in families of lower socioeconomic status, although some argue that this could be the result of “drift down” toward poverty that occurs as individuals’ dysfunctions prevent them from participating in activities such as employment (Hirsch & Weinberger, 2003; Shean, 2004). Also, interesting to note is that individuals with schizophrenia are 5-10% more likely to be born in winter and early spring months than the general population, which brings about theories involving mothers’ exposure to flu viruses during pregnancy (Shean).

### **Etiology**

Numerous theories abound citing causes for schizophrenia, including obsolete ideas as the “schizophrenogenic mother,” but it is now widely accepted to be a disease of the brain (Buckley, 2008; Hirsch & Weinberger, 2003; Shean, 2004; Torrey, 2006). The focus on schizophrenia as a disease of the brain has resulted in an increase of research in areas such as brain anatomy, neurocognition, and heredity (Buckley; Shean; Torrey). Genetics are currently a major focus of research in the field as genes and gene combinations are discovered that may contribute to the development of new treatments (Buckley). Despite a number of theories, the etiology of schizophrenia is considered to be extremely complex, alongside other severe mental illnesses such as bipolar disorder, and environmental factors continue to play a key role in hypotheses (Buckley; Hirsch & Weinberger; Torrey).

Stress theories have also received much attention as a cause for schizophrenia (Torrey, 2006). Stresses that have been proposed to be a major cause of the illness include childhood trauma such as abuse, military battles, or other traumatic life events.

Other contributing factors that have been explored with some acceptance include nutrition, endocrine, infection, development, and neurochemical dysfunction (Torrey). Fortunately, old-fashioned beliefs such as masturbation, evil spirits, or bad parenting have all but vanished (Torrey).

Although bad parenting theories have begun to dissipate, other theories involving family members are still supported. One of the prominent environmental and social stress theories is that involving the influence of family members who are over involved and critical, termed high *expressed emotion* (EE) (Hirsch & Weinberger, 2003). In short, expressed emotion (EE) refers to the emotional climate in the home (Tarrier & Barrowclough, 1990). Also remarkable is that professional caregivers who are not relatives characterized as high EE have also been identified as influencing reactivity in patients with schizophrenia (Hirsch & Weinberger).

The basis for this commonly studied theory is that family members who are hostile, lack warmth, and who become over involved and critical actually contribute to higher rates of relapse and non-adherence for the mentally ill relative (Hirsch & Weinberger, 2003; Rudge & Morse, 2004). Persuasive evidence exists to support the notion that individuals with schizophrenia demonstrate social reactivity in the face of a stressful family atmosphere (Hirsch & Weinberger).

Despite the compelling evidence that high EE relatives contribute to relapse rates, this line of inquiry has been criticized for its implied blame toward families (Lefley, 1996; Tarrier & Barrowclough, 1990). Objections are based on the accusation of family members in causing schizophrenia, and the seeming lack of support for family members

who care daily for their relatives with chronic mental illnesses (Lefley, 1996). Furthermore, in the expectation of family members to avoid relapse and uphold medication adherence, they are also blamed for the continuance of their loved ones' mental illness (Rudge & Morse, 2004).

### **Functional Outcomes and Quality of Life**

Considering the many severe expressions of schizophrenia, it is not surprising that individuals are frequently disappointed and demoralized about the trajectory of their lives (Hirsch & Weinberger, 2003). The lives of individuals are often affected on a daily basis by symptoms of schizophrenia. Therefore, it is apt to consider aspects of function and the global manifestations of this illness on one's life. For the occupational therapist, this understanding is paramount.

The chronic nature of schizophrenia is accompanied by longstanding problems in the management of everyday life activities (Hirsch & Weinberger, 2003). These include, but are not limited to dysfunction in areas of employment, self-care, social, and leisure tasks (Hirsch & Weinberger; Torrey, 2006). Individuals with schizophrenia are often bound to support from other people to help them accomplish necessary tasks (Lefley, 1996; Torrey). Therefore, although some individuals with schizophrenia are able to live independently, many must live with family or other caregivers (Lefley, 1996; Torrey).

One important contributor to reliance on other people such as family members is that many individuals with schizophrenia are not able to sustain employment due to interference of symptoms (Hirsch & Weinberger, 2003; Torrey, 2006). Estimates of individuals who are able to sustain full-time work are as low as 6% (Torrey). Although

part-time employment is at times feasible, individuals struggle to socialize with others in addition to enduring other positive and negative symptoms while trying to complete productive tasks (Torrey, 2006). So, individuals are reliant on family or other disability incomes such as social security in order to manage their financial needs (Torrey).

Quality of life has also found to be poorer in individuals with schizophrenia (Cara & MaCrae, 2005). For example, in a grounded theory study by Gee, Pearce, & Jackson (2003), six participants with schizophrenia indicated that a vast array of factors detracted from quality of life. These included factors such as a) reduced control, b) barriers placed on relationships with others, c) loss of opportunity to fulfill work roles, d) financial constraints, e) subjective experience of psychotic symptoms, f) side effects and attitudes to medication, g) psychological responses to living with the illness, h) labeling by others, and i) concerns for the future.

As a result of these severe functional implications, individuals with schizophrenia often live with stigma by society toward their mental illness (Cara & MaCrae, 2005; Torrey, 2006). Conversely, recovery for individuals with mental illness is negatively impacted by the deleterious effects of stigma (Cara & MaCrae). Individuals with mental illness are often the subject of judgment by other people, usually in response to lack of understanding and education in the area of mental illness ([www.nami.org](http://www.nami.org)). Media portrayals of individuals with mental illness as violent perpetrators of crime add to this dilemma (Torrey).

Beyond the detrimental effects of stigma by society, individuals with schizophrenia may begin to self-stigmatize, a way of internalizing the stereotypes that

society places upon them (Watson, Corrigan, Larson, & Sells, 2007). This form of stigma has been found to have an interesting relationship with the ways in which individuals with mental illness work toward their life goals.

Corrigan, Larson, & Rusch (2009) applied the “why try” phenomenon in their conceptualization of self-stigma and impact on life goals. They explained that decreased self-esteem and self-efficacy potentially deters pursuance of opportunities that lead to achievement of life goals. Individuals are not only aware of labels given to them by society, but they internalize the label which contributes to demoralization. Consequently, they do not feel competent or worthy to do what is necessary to meet life goals (Corrigan, Larson, & Rusch).

### **Pharmacological Treatment of Schizophrenia**

*Antipsychotic or neuroleptic* medication is the primary mode of treatment for schizophrenia, followed by other non-pharmacological interventions to manage the behavioral and functional implications of the illness (Hirsch & Weinberger, 2003; Shean, 2004). Antipsychotic medications aim to reduce psychotic effects of schizophrenia, such as hallucinations and delusions, through a variety of mechanisms usually involving dopamine and serotonin systems (Buckley, 2008; Hirsch & Weinberger). It is estimated that approximately 60-70% of individuals with acute psychoses demonstrate improvement on antipsychotic medications (Shean).

Evidence has shown that medications are effective in conquering positive symptoms and in delaying relapse of symptoms, although complete remission of symptoms with medications only occurs for approximately 25-35% (Shean, 2004; Torrey,

2006). Antipsychotic medications have not been reported to assist with the majority of negative symptoms including anhedonia, social withdrawal, apathy, and flat or blunted affect (Johnson, 1998; Shean). Unfortunately, it is negative symptoms that have been shown to be more closely linked with poorer functional outcomes (Johnson; Torrey).

With the advent of second generation, or *atypical* antipsychotics, the overwhelming side effects once experienced with typical antipsychotics were reduced and generally more tolerated (Shean, 2004). Examples of atypical antipsychotics include olanzapine (Zyprexa), clozaril (Clozapine), risperidone (Risperdal), quetiapine (Seroquel), and ziprasidone (Geodon). By the same token, side effect profiles of new antipsychotics remain substantial. Some of the more bothersome side effects include excessive weight gain, fatigue, and extrapyramidal symptoms (Shean). Specifically, atypical antipsychotic medications are associated with a risk for metabolic syndrome, which includes characteristics of obesity, insulin resistance, and lipid abnormalities (Hirsch & Weinberger, 2003).

### **The Complex Issue of Medication Adherence**

*“For me, the treatment is far worse than the illness. It did not stop me thinking I was special, but I lost the ability to do my mission...I could not even do simple things like cook proper meals, let alone think clearly or develop other coping strategies.”* (Hirsch & Weinberger, 2003, p. 705).

Antipsychotic treatment is considered the first line of defense in the treatment of schizophrenia (Hirsch & Weinberger, 2003; McCann, Clark, & Lu, 2008; Torrey, 2006). Despite overall improvements in the side effect profiles of newer generation

antipsychotics, adherence to medications has not improved (Kikkert et al., 2006; McCann, Clark, & Lu; Velligan et al., 2009). The emotional, social, familial, and economic consequences of non-adherence are far-reaching, which will be discussed later in this section. Due to the enormity of the problem, medication adherence research is designated to be a key objective by the World Health Organization (WHO, 2003).

Before examining the problem of non-adherence, it should be noted that some hold tightly to the belief that medications are not only unnecessary, but inhumane, in the treatment of psychiatric conditions (Breggin, 2008; Torrey, 2006; Watson, 2003). Some groups rebel against the use of psychiatric medication; for example, those who support the beliefs of Thomas Szasz, who denies the existence of schizophrenia, or scientology, which discounts the use of pharmacological interventions for any reason (Torrey).

In particular, some researchers in the psychiatric field have suggested other negative consequences of taking medications such as changes in the brain, decreases in function, risk of suicide or homicide, and other long-term ill effects (Breggin, 2008; Watson, 2003). Also, as discussed previously, long-term use of antipsychotic medications have been associated with an increase in morbidity and mortality, particularly due to effects such as metabolic syndrome (McCann, Lu, & Clark, 2008). However, this topic is controversial to say the least, and reveals mixed opinions in the literature (Hirsch & Weinberger, 2003).

### **Scope of the Problem**

But for many individuals with schizophrenia, a reduction or omission of symptoms has occurred as a result of psychiatric medications and can be said to benefit

from them (Lieberman et al., 2005; Roe, Goldblatt, Baloush-Klienman, Swarbrick, & Davidson, 2009). However, individuals with schizophrenia do not always take their medications as prescribed.

It is estimated that approximately half of all patients with schizophrenia who start antipsychotic medications will stop taking them within one year and 75% will stop taking them within two years (Gray, Robson, & Bressington, 2002; Lieberman et al., 2005; Roe et al., 2009). Although the scope of the problem reveals mixed results in the literature, a number of reviews have reflected non-adherence rates between 50%-70% for individuals with schizophrenia (Kikkert et al., 2006; Rettenbacher et al., 2004; Velligan et al., 2009; Zygmunt et al., 2002).

The problem of non-adherence is not restricted to individuals with schizophrenia. Others with chronic illnesses such as asthma, high blood pressure, rheumatoid arthritis, and diabetes have similar rates of medication adherence (Marland & Cash, 2005; Rogers et al., 1998). Therefore, the issue potentially stems beyond incapacities associated with insight and cognition, which will be discussed later.

Medication adherence is best viewed along a continuum, and is rarely an all or nothing mechanism (McCann, Clark, & Lu, 2008; Velligan et al., 2009). Most individuals are partially adherent to medications, choosing to take some of their medications some of the time (Donohoe et al., 2001; Hamer, 2006; McCann, Clark, & Lu; Patterson et al., 2002; Velligan et al.). Also, strict dedication to a particular medication regimen may also be regarded as non-adherence (Bebbington, 1995). Seeking out too much medication may be seen as an additional extreme in the continuum

of non-adherence, although this form of self-medication does not appear to be included in the studies that were reviewed thus far.

### **Paradigm Shift**

Whereas this very issue was referred to in recent years as *compliance*, a paradigm shift has been suggested to move toward *adherence* or *concordance* (Gray, Robson, & Bressington, 2002; Gray, Wykes, & Gournay, 2002; Seale et al., 2006). Compliance has been criticized because of implied power issues, with the provider taking charge and the client submissively tagging along (Seale et al.). Compliance terminology accentuates the view of an individual who is unmotivated or difficult. Unfortunately, this type of authoritative relationship is archetypal of providers and patients within the existing medical model (Bebbington, 1995).

It has been argued that behaviors exhibited by patients are largely based on expectations held by providers (Roe et al., 2009; Rogers et al., 1998). The new language of adherence and concordance are recommended to highlight the important role of the individual with illness as a person capable of partnering in decisions around personal health care, to de-emphasize perception of power by providers, and to reduce blame toward individuals with illness (Gray, Wykes, & Gournay, 2002; Seale et al., 2006).

Therefore, a transformation of attitudes toward the individual with illness is proposed to accompany changes in rhetoric, to avoid blaming the person, and to rather understand the human condition (Bebbington, 1995; Bunn et al., 1997; Gray, Wykes, & Gournay, 2002; Seale et al., 2006). Certainly, most can likely recall a time in life when

antibiotic or other similar regimens were not followed exactly as prescribed.

Nonetheless, as common as this problem may be, it has serious implications for those living with serious mental illnesses such as schizophrenia, which will be discussed later.

### **Factors Contributing to Medication Non-Adherence**

Influences involved in the decision of individuals with schizophrenia to adhere, or not, to medications have included features of the person's illness, social environmental impacts in the medical community and public at large, economic environmental factors, and properties of antipsychotic medications (Velligan et al., 2009; Weiden, 2007).

Personal characteristics that may be involved include severity and persistence of illness symptoms, poor insight, self-stigma, and beliefs in efficacy of treatment and about quality of life (Bebbington, 1995; Bunn et al., 1997; Diamond, 1985; Fung, Tsang, & Corrigan, 2008; Kikkert et al., 2006; Rettenbacher et al., 2004; Santone et al., 2006; Velligan et al., 2009).

Commonly, social influences that have been cited as impacting medication adherence include less social support from others, poorer treatment alliance with prescribers and societal stigma (Day et al., 2005; McCann, Clark, & Lu, 2008; Rettenbacher et al., 2004; Roe & Swarbrick, 2007; Tarrier & Barrowclough, 1990; Velligan et al., 2009; Weiden, 2007). Economic influences include difficulty that individuals have with accessing prescriptions due to poverty and lack of access to health care (Velligan et al.).

Finally, properties of medications that have been adequately supported in the literature include side effects of medications, such as weight gain and fatigue

(Rettenbacher et al., 2004; Velligan et al., 2009). Remarkably, however, side effects as an influence in non-adherence have produced a wide range of conflicting results (Kikkert et al., 2006; McCann, Clark, & Lu, 2008).

So, individuals with schizophrenia or schizoaffective disorder are non-adherent to medications for a variety of reasons, in no order of priority, including: a) severity of symptoms, b) level of insight, c) belief in efficacy of treatment, d) cognitive ability, e) negative symptoms, f) medication side effects, g) frequency and ease of routine, h) costs, i) stigma, j) social support, k) alliance with providers, l) attitudes and beliefs about quality of life, m) belief that medications are no longer needed, and n) co-morbid substance misuse (Diamond, 1985; Gray, Wykes, & Gournay, 2002; Hamer, 2006; Kikkert et al., 2006; Marland & Cash, 2005; McCann, Clark, & Lu, 2008; Rettenbacher et al., 2004; Roe & Swarbrick, 2007; Velligan et al., 2009).

Based on the expert consensus of the available literature on non-adherence, Velligan et al. (2009) endorsed the following influences as most relevant to non-adherence: a) poor insight or lack of illness awareness, b) distress from side effects or fear of side effects, c) inadequate efficacy of treatment to manage persistent symptoms, d) believing medications are no longer needed, e) the side effect of weight gain for individuals with schizophrenia (versus sedation for bipolar disorder), and f) persistent positive or negative symptoms in schizophrenia (p. 6). Some features are seen as more or less prominent in the literature, but reviews remain inconsistent as to the importance of many of these factors in non-adherence (Gray, Wykes, & Gournay, 2002; McCann, Clark, & Lu, 2008; Velligan et al.).

## Consequences

Though scope and epidemiology of non-adherence continues to perplex researchers and clinicians, it is widely acknowledged that non-adherence leads to serious implications. Medication adherence has been cited as the most “robust predictor of 5-year outcome” for consumers who have experienced their first episode of psychosis (Miller, 2008). Of course, medication non-adherence is ever present from the first episode and beyond (Hirsch & Weinberger, 2003; Weiden, 2007).

The substantive impact of non-adherence to psychiatric medications include: a) more frequent and cyclical hospitalizations, b) increase in psychotic relapse rates, c) deterioration of function, d) increase in symptoms, e) poorer outcomes, f) increase in arrests and violence, g) decreased life satisfaction, h) decreased mental ability, i) increase in substance use, and j) increase in suicide risk (Bebbington, 1995; Donohoe et al., 2001; Estroff et al., 1994; Fenton, Blyer, & Heinssen, 1997; Hamer, 2006; Law, Soumerai, Ross-Degnan, & Adams, 2008; Velligan et al., 2009).

Each of these consequences has implications for the individual, but also for families and societies (Bebbington, 1995; Velligan et al., 2009; Weiden, 2007). Families who care for loved ones who are not adherent to medications must manage the aftermath of more frequent relapses, leading to instability and intense conflict within the family unit (Jungbauer, Stelling, Dietrich, & Angermeyer, 2004). Healthcare costs associated with increased relapse rates and use of hospital services can be as much as four times greater than those who do not relapse (Law et al., 2008; Velligan et al.). In addition, the severe consequence of homelessness can be a predictor and an outcome of medication non-adherence (McCann, Clark, & Lu, 2008).

## **Interventions**

A number of multi-disciplinary interventions have been attempted to improve rates of adherence. At the individual level, interventions have included education, cognitive behavior strategies, environmental cues, alterations to ease medication routine, intermittent medications, long-acting injectable or “depot” medications, and “quick dissolve” formulas to discourage “cheeking,” or hiding, pills in the mouth for later discard (Godemann et al., 2003; Gray, Wykes, & Gournay, 2002; Hamer, 2006; Jarboe, Littrell, & Tugrul, 2005; Zygmunt et al., 2002). At the community level, policies and programs, such as outpatient commitment laws, have been enforced with questionable rates of success within the chronically under-funded mental health system (Appelbaum, 2001; Allen & Smith, 2001; Hoge & Grottole, 2000; Munetz, Geller, & Frese, 2000; Swanson, Swartz, Elbogen, Wagner, & Burns, 2003; Swartz et al., 1999).

Zygmunt et al. (2002) performed an extensive review of the literature concerning interventions for medication non-adherence. They suggested that, in order to improve rates of non-adherence, educational strategies must reach beyond the knowledge level. Instead, they recommend that interventions must be aimed toward attitudes and behaviors in order to be successful. Furthermore, interventions that have focused on family support have also been unsuccessful.

It is also significant to point out that earlier interventions have been cited as a potential need for research and intervention (Hirsch & Weinberger, 2003; Miller, 2008; Reyers, 2010). This is based on the suggestion that outcome for medication adherence may be linked with the stage in which individuals seek their first treatment (Hirsch & Weinberger, 2003). The first treatment connection is typically not made until

approximately one year after onset of initial symptoms. The duration of untreated psychosis (DUP) has been linked, although not with certainty, to an unfavorable course of illness (Hirsch & Weinberger; Miller). Some researchers believe that beginning antipsychotic treatment early in the illness course may help to improve chances of a favorable response, thereby improving chances for better function (Hirsch & Weinberger; Miller; Reyers).

### **Uncovering Complexity**

The number of potential influences involved in non-adherence is overwhelming (Velligan, 2009; Weiden, 2007). As stated, the reality is that a number of influences are probably involved when considering the complexity, non-linearity, and multiple layers of the problem (McCann, Clark, & Lu, 2008; Velligan et al.; Roe et al., 2009; Roe & Swarbrick, 2007; Weiden, 2007; Zygmunt et al., 2002).

Review of the literature cannot help but create more questions than answers to this problem. For example, insight as a key influence in non-adherence has perhaps been one of the most argued in the literature. In fact, results as to its relevance are quite mixed (Holzinger et al.; McCann, Clark, & Lu, 2008). Cognitive ability level is another characteristic that has revealed inconsistent findings as relative to medication non-adherence (Holzinger et al., 2002; Jarboe & Schwartz, 1999; McCann, Clark, & Lu). These controversial findings have led to questions as to whether individuals who have disrupted insight and cognition are capable of entering into a decision-making process about their medications (Davidhizar, 1985; Davidson et al., 2009; Marland & Cash, 2005; McCann, Clark, & Lu, 2008; Smith, Hughes, & Budd, 1999; Roe et al., 2009).

However, evidence that supports individuals' abilities to engage in reflecting upon their experiences with medications is increasingly seen in the literature (Davidhizar, 1985; Krutis, Robertson, & Paul, *in progress*; Marland & Cash, 2005; Roe et al., 2009). Beyond reporting their experiences, individuals with schizophrenia are participating in complex decisions about whether medications will be internalized as an acceptable treatment in their recovery (Holzinger et al., 2002; Marland & Cash; Roe et al.). This information is particularly relevant to this study as subjective experiences were sought from participants. It is also useful to consider this aspect of the adherence literature with regards to occupational therapists as facilitators in consumers' goals to achieve lives filled with meaning, despite residual symptoms such as poor insight.

### **Qualitative Studies on Medication Adherence**

Research studies on medication adherence tend to focus on quantitative methodology using correlational designs (McCann, Clark, & Lu, 2008; Roe et al., 2009; Zygmunt et al., 2002). However, given the large number of influences that may be involved in reasons behind non-adherence, non-replication of existing research, heterogeneity of the illness, and the complex interaction of environmental components present in each life, it is difficult to know from existing literature which characteristics are predominant (McCann, Clark, & Lu; Velligan et al.; Weiden; Zygmunt et al.). A potential result of the ambiguity is that adherence rates have remained unchanged in the past four decades (Kikkert et al., 2006).

Roe et al. (2009) suggest that use of qualitative methods should be utilized for exploration of this problem, as more research is pointing to the influence of personal impacts such as culture, stigma, and attitudes. These authors conducted a qualitative

study using semi-structured interview questions with seven individuals with serious mental illness to explore why and how decisions are made to stop taking prescribed medications (Roe et al.). Each of the seven participants had taken psychiatric medications in the past, but stopped taking them within the year before the study. Four were diagnosed with schizophrenia spectrum disorder and three reported having bipolar disorder.

Descriptive analysis revealed that individuals encountered a five stage process when they chose not to take medications. The process began with the emotional crisis that initially called for medication use and ended with the decision to stop taking medications based on the development of personal perspectives about medications (Roe et al., 2009). However, a process was found to occur amid these two ends of the spectrum.

After the initial crisis, participants suggested that they moved toward the second stage concerning their subjective experiences of taking medications (Roe et al., 2009). Within this stage, participants revealed their perceived losses, such as what may occur as a result of side effects that interfere with thinking and aspects of self. Also, participants attributed personal meaning to medication taking, again reporting on their perceived losses to self-concept and the symbolism of medications as entering a new world of psychiatric illness. Individuals also described feelings that they ascribe to taking medication, such as humiliation and despair. Some also expressed frustration with their providers regarding attitudes that seemed demeaning and indifferent with regard to medications in their lives (Roe et al.).

Stage three is described as the actual conflict of adhering or not adhering to medications (Roe et al., 2009). As the multi-step process implies, this decision was not sudden but grew out of preceding thoughts and doubts about whether medications were right for them. Interestingly, sources of external control such as professionals and family members were discussed here by participants. They revealed their struggle with trying to please others who thought medications were necessary to manage the illness, as well as the controls put in place by mental health system itself (Roe et al.).

Participants described their resolution of the conflict in the fourth stage, whereby more internal control, awareness, and security were gained in order to support personal decisions regarding medication (Roe et al., 2009). In addition to a new awareness and internal sense of confidence, some participants felt they had support from other people and were not alone.

However, it is important to note that some participants described the continuing views of non-acceptance of their decision to stop medications from others, such as psychiatrists and families (Roe et al., 2009). The decision on the part of each of these participants was to stop medication, as this criterion was sought for the study. Remarkably, participants felt their decision was personal and did not attempt to make blanket statements about what may be right for other people. Some even remained open to resuming medications in the future should their symptoms worsen (Roe et al.).

One of the most striking areas for discussion based on this study was that individuals with severe mental illnesses were able to describe their process of analyzing their perceived benefits versus losses regarding medication before settling on a decision

(Roe et al., 2009). Participants' rationales did not seem to suggest poor insight when medications were viewed within the context of their life experiences. Rather, their decisions to stop medication were more often a result of negative experiences and feelings about medications, or an opposing viewpoint to that of their physician. So, the results of this study seem to differ from perspectives of loss and disability in schizophrenia, but are more fitting with studies on recovery in mental illness (Davidson, et al., 2009).

This concept is further highlighted in other recovery literature that addresses whether or not insight is required for recovery (Davidson et al., 2009). The recovery model would say that insight, in the sense of being aware of pessimistic outcomes of schizophrenia, is not required to move forth in recovery (Davidson et al.). And, as these authors note, the majority of individuals with severe mental illness and accompanying poor insight, are still able to demonstrate insight into the fact that their lives have been terribly impacted by the illness (Davidson et al).

Another useful study by Marland and Cash (2005) utilized grounded theory to explore medication decisions by comparing those with schizophrenia to individuals with asthma and epilepsy. They discovered a core category of "responsive resolution" which referred to individuals' process of responding to the issue of medication adherence using logical decision-making.

In essence, participants revealed a variety of decision-making styles by discerning aspects of their illness, and reacting through a mechanism of fear of relapse (Marland & Cash, 2005). Participants attempted to achieve an optimum balance of benefits and risks

relative to medication taking. Their decision-making strategies rivaled one another in terms of comparison between those with schizophrenia versus physical conditions such as asthma. The authors suggest that, although it is important to understand special features involved in certain conditions, it is also essential to understand that decision-making is a process, no matter the diagnosis, that seems to change and cycle over time (Marland & Cash).

Another pertinent view of medication adherence and impact on self-identity is offered by Karp (2006) who gathered qualitative data from participants with severe depression. Although studies on depression do not necessarily equivocate to studies on schizophrenia, the fact that each is a severe mental illness with intense consequences to daily life makes them worthy of regard. However, it is true that most individuals with schizophrenia experience thought disorders that are different from those with depression (Hirsch & Weinberger, 2003). Therefore, it can be theorized that experiences surrounding medication adherence could differ in some aspects between the groups.

But, as Karp (2006) proposes, all chronic illnesses, including those that are physical in nature, greatly affect self-identity. Where psychiatric medications are concerned, however, there exists an even deeper impact on the self (Karp). This impact could occur as a result of stigma by society, such as the view that medications are crutches or signs of weakness, or because one questions whether he remains the person he was before medication changed his brain function (Karp). Similarities are indeed present among the severe mental illnesses, and are deserving of some attention as it may pertain to the issues surrounding those with schizophrenia.

In Karp's book (2006) entitled "Is it Me or My Meds?" participants with depression expose their innermost thoughts about the impact of medications on self-identity. Even when individuals decided that taking medications was acceptable, they still wondered whether they were their authentic selves when taking them. Some longed to know who they really were aside from their medications, and admitted to difficulties in identifying whether changes were a result of medications versus other influences in their lives such as career, family, or exercise (Karp).

Through others' impressions of struggles with self-identity, Karp (2006), who himself lives with depression, emphasizes the notion of being "married" to medication." He uses this analogy to highlight the changing nature of feelings about medications from "first swallow" or the honeymoon phase, to the subsequent phases of a love-hate relationship that sometimes ends in "divorce" (Karp, p. 64). For example, individuals in the honeymoon phase of taking psychiatric medication may experience an emotional high similar to that of falling in love. Trying medication for the first time may symbolize hope for improvement or cure (Karp). If medications are later discovered to be less effective than hoped for, individuals may experience disillusionment and disappointment with their medications. Depending on the unique process, the outcome can vary from satisfying, lifelong commitments to divorce from medications (Karp).

Pettie and Triolo (1999) also conducted a qualitative study about recovery, with a particular emphasis on exploration of self constructs. Although they did not explore medication adherence as a construct, this study describes the battle for self-identity that occurs within the evolution of the illness process. In fact, participants in the study revealed that their personal identity suffered as a result of accepting professional advice.

One participant stated “If I agree with you that this is what I need, then I’ll be agreeing that this is what I am.”

Ng et al. (2008) also set out to define Chinese consumers’ perspectives of recovery using a focus group strategy. One of the findings in this study pertained to the relationship of medication to recovery. Participants with schizophrenia felt recovery could not be achieved until they stopped medications and held a steady job. In addition, participants also described recovery as including the ability to function in other important areas of life such as work, relationships, and independent living (Ng et al.). So, in this study, it appears that success in other meaningful occupations such as work may be complexly related to medication adherence.

So, many current studies are beginning to support the idea of the complexity of medication non-adherence and the possible impacts to self-identity, empowerment, and self-esteem (Karp, 2006; McCabe, Saidi, & Priebe, 2007; McCann, Clark, & Lu, 2008). Studies have also pointed to the meanings of medication that perhaps stem from society, leading to the idea that social control is a powerful influence behind those who support psychiatric medication use (Rogers et al., 1998; Seale et al., 2005). These findings have contributed to the recommendations of some researchers and mental health advocates to understand medication adherence as a process; one that is inclusive of many dimensions that are not yet well-understood (Kikkert et al., 2006; McCann, Clark, & Lu; Roe & Swarbrick, 2007; Zygmunt et al., 2002).

### **Families of Individuals with Schizophrenia**

*“You couldn’t conceive of a situation in which a relative wouldn’t call you if your wife had severe diabetes. But if it’s a mental illness, forget it. No calls, no casseroles, nothing.”* (Carol Grogan as cited in Wasow, 1995, p. 61).

Caring for an ill family member, aptly referred to as “an uncertain inheritance” in a recent book by a mental health journalist, Nell Casey, symbolizes the nature of how illness enters ones’ life in an often unexpected manner (2007). The uncertain inheritance refers to the unanticipated introduction of sickness, hospitals, medications, and needs that will perhaps last a lifetime. And as the quote by Carol Grogan so movingly implies, families who are surviving the onset of an illness like schizophrenia do not receive any special treatments as may be standard in the case of physical disabilities. There will be no casseroles.

Yet, our culture partly determines what expectations are left to the non-disabled family (Hines, Preto, McGoldrick, Almeida, & Weltman, 2005; Lefley, 1998). That is, family members may be called to step up unexpectedly, without regard for one’s own life goals, and go to the rescue of a disabled loved one. In the process of this life change, families may be summoned to add care giving tasks to the already long list of “to do’s” in life. Along the way, as the various essay writers reveal in Casey’s (2007) book , many emotions are certain to rear their ugly head including guilt, anger, depression, restlessness, and ambivalence.

Family experiences are a neglected topic in the field of schizophrenia (Breier & Strauss, 1984; Jungbauer & Angermeyer, 2002; Lefley, 1997; Lefley, 1996). Three

general topic areas appear to be present in the family literature on schizophrenia including family as etiology, caregiver burden, and family as a social support (Jungbauer, Stelling, Dietrich, & Angermeyer, 2004). Surely, most of the research that exists centers on family as a pathogenic contributor to the illness itself and relapse, whether through obsolete theories like the “schizophrenogenic mother” to widely accepted theories like that of expressed emotion (Jungbauer et al., 2004; Lefley, 1996; Torrey, 2006). Historically, families have been seen as a contributor to relapse and are often blamed for failures in medication adherence for their mentally ill relatives (Brekke & Mathieson, 1995; Larson & Corrigan, 2008; Lefley, 1996).

Meanwhile, they are the primary persons in carrying out the overwhelming responsibility of monitoring medication and watching for signs of impending trouble, particularly after de-institutionalization in the 1970’s (Lefley, 1998). Medication adherence is indeed an issue that impacts the person with illness, but also families who likely serve integral roles within the consumer’s social environment. In order to understand how medication adherence may be experienced by individuals and families, it is important to consider typical developmental life cycles as a starting point. Of course, with the onset of a severe mental illness, these typical developmental tasks are likely to go unmet, which will also be discussed in depth later.

### **Typical Individual and Family Life Cycles**

Life cycles of individuals and families are important to understand in order to piece together impacts in the advent of chronic mental illness. Life cycles, in essence, are the ways in which human beings develop and grow throughout the lifespan (Carter & McGoldrick, 2005). Individuals are born into a family system from the very beginning of

life, and are influenced greatly in development within the context of the family (Carter & McGoldrick).

Through collective experiences in life, individuals and families are connected across generations, bound by history (Carter & McGoldrick, 2005). Unlike other nonfamily systems, families acquire members through birth, adoption, or marriage and cannot choose to disband themselves. The life cycle is not constant and linear, but it is always changing and being redefined among members of the family (Carter & McGoldrick). This is true whether or not chronic illness enters into the equation.

Although stages seem an obvious way to organize time and transitions, it is important to realize that stages of life are not an exact science, but more so a guideline to consider (McGoldrick & Carter, 2005). Equally significant is the intersection between one's individual life cycle and that of the family life cycle, which can result in challenging dynamics as family members may have differing needs from one another (McGoldrick & Carter). These dynamics occur in "normal" family life, and are significant to inform understanding of ways that dynamics can be changed, exaggerated, or diverted in the face of severe mental illness.

### **Adolescence and early adulthood.**

As reviewed in the literature about schizophrenia, individuals typically experience the onset of mental illness in late adolescence and early adulthood years, at the cusp of when one would typically be pursuing college education, establishing more independence apart from family, developing relationships with other people, and finding satisfying work (Hirsch & Weinberger, 2003; Torrey, 2006; McGoldrick & Carter, 2005).

Considering the developmental life cycle of the individual, these are periods of time that hold significant meaning for one's development of self (McGoldrick & Carter).

Adolescence is generally viewed as the time period between ages 14 and 21 years, when individuals are searching for an identity for themselves and carving out their own future as young adults. At this stage, individuals begin to look outside of themselves and recognize the needs of other people. The development of morals, values, and spirituality is also typical during this period of time (McGoldrick & Carter, 2005).

Although adolescents have developed other support networks, namely friendships and relationships with significant others, parents continue to have strong potential influences on their children (McGoldrick & Carter, 2005). In this stage of the family life cycle, parents must determine ways of handling power struggles with their adolescent children, guide them in choosing friends wisely, provide more freedom rather than restriction, facilitate their awareness of dangers, and advise them regarding life decisions. Generally, the task of adolescent parenting revolves around preparing the young person for separation from the original family unit (McGoldrick & Carter).

Early adulthood occurs between the ages of 21 and 35 years (McGoldrick & Carter, 2005). This stage of the life cycle is characterized as the development of committed relationships and engagement in satisfying work (McGoldrick & Carter). With the onset of new emotional and financial freedom, individuals are now able to more independently care for themselves and other people. The focus at this stage is the attainment and maintenance of one's own commitments such as education, career, marriage relationships, and parenthood (McGoldrick & Carter).

During this time period, individuals also gain more maturity in issues of sexuality for oneself and others (McGoldrick & Carter, 2005). Young adults are also characterized as being more self-involved, particularly in the time frame before marriage and family obligations increase (Fulmer, 2005). Though young adults may live separately from their original families, they remain dependent on their families for emotional support (Fulmer).

Gender differences may come into play, as with other stages, as males are seen as strong autonomous providers for their own families and females may have taken on roles as wives and caretakers (Fulmer, 2005). Therefore, types of emotional support that male and female children seek from their families may be fundamentally different in nature. It is also possible, for example, that females may have taken on working roles as has been common since the 1960's (McGoldrick & Carter, 2005). Therefore, a daughter could seek emotional support and advice from her father if her mother did not work, which is entirely plausible given the generational gap.

Important to note is that many young adults temporarily return to their parents' homes after college for a number of reasons, including financial, as they prepare for adulthood (Fulmer, 2005). Consequently, parents of adult children may be taken aback by this return. They may have reached an emotional acceptance of what was an empty nest, only to experience the resurgence of parenting responsibilities and uncertainty regarding their own life plans (Fulmer).

However, young adults may not be married or have children yet and still rely on their families of origin for a number of other reasons related to development of productivity and relationship building (Fulmer, 2005). Families help to set examples for

their young adult sons and daughters, advising them on strategies to enable career development and to pursue intimate relationships with other people. It is not uncommon, however, for young adults to feel a “polite contempt” toward their parents; perhaps feeling ostentatious about their abilities to circumvent mistakes once made by their parents (Fulmer, p. 217).

### **Families of adolescents and young adults.**

Parents in this stage of the family life cycle try to pass on values and family traditions as their adult children phase into their own work, religious practices, and family life (Fulmer, 2005). If adult children choose to depart from values and traditions of their family, this may be a particularly difficult time for parents as they are called to refine their expectations. It is also possible that parents wish for their children to avoid taking risks or making the errors that they themselves may have made in their young adulthood. This can produce conflict between parents and adult children since this can be construed as criticism (Fulmer).

Parents of adolescent and young adult children experience a transformation in the family structure during these critical stages of development (Preto, 2005). Parents, who are in the middle adulthood stage of the life cycle, although diverted from the physical strains of raising young children, must continue to undergo emotional shifts in relationships with their emerging young adults. In adolescence, parents must handle physical, sexual, and emotional changes in their children. As the adolescent child demands more independence, families must respond by renegotiating roles and patterns of relating (Preto).

Other family members, such as siblings and grandparents, are likely experiencing their own adjustments within the life cycle (Preto, 2005). Middle adulthood can signify the difficult challenges of the sandwich generation as parents care for young adult children and their own aging parents. This time period can be particularly challenging when parents do not have support from other family members or the community (Preto). Some cultures, such as Puerto Rican parents, rely on extended family members to assist them with raising their adolescents. But white middle class families of today tend to lack this type of extended support that once was a part of mainstream American life (McGoldrick & Carter, 2005).

Midlife is a time period that can span upwards of 20 years due to new expectations of health and longevity (Blacker, 2005). This stage is known by some as *the empty nest*, and for others as *launching children*. Contrary to what some may imagine is a period of depression for parents, launching children is actually a happier and more fulfilling time (Blacker). Mothers in particular have expressed that they welcome this time period, when they can resume life interests that may have been put off during the busy time of raising children (Blacker). In addition, most individuals in midlife are healthy, energetic, and ready to move forward with a meaningful life.

Also important to note is that culture also influences life decisions, such as how independent adult children should be (Blacker, 2005; Lefley, 1998). Caucasian parents, for example, will expect to support their children less than African-American or Dutch families (Blacker). Therefore, the impact of illness in an adult child of parents in midlife will vary according to culture in aspects such as cohesiveness and role expectations (Blacker).

## **Mental Illness and the Life Cycle**

*“The ways in which a family adapts to its tasks will likewise influence how individuals negotiate their individual development”* (Carter & McGoldrick, 2005, p. 36).

Family relationships are significant to the issue of illness management, since upwards of one to two thirds of adults with schizophrenia are residents of their parents’ homes (Brekke & Mathieson, 1995; Gallagher & Mechanic, 1996; Lefley, 1996). The “original family” of the individual with schizophrenia serves as the most significant social contact (Jungbauer & Angermeyer, 2002). Research has shown that the social network of individuals with severe mental illness is small and highly dependent on family members (Carpentier, 2006; Jungbauer et al., 2004). This is particularly so after the event of deinstitutionalization, where families became the likely sources of care for individuals in need of continued social support in order to successfully live in the community (Lefley, 1998).

The Family Systems-Illness Model can be used to inform the complex interconnectedness of the illness, individual, and the family life cycles (Rolland, 2005). Certainly, the onset and continuation of a chronic illness such as schizophrenia, causes rippling effects throughout the individual and family’s lives. Schizophrenia causes many complications to ones development (Jungbauer, Stelling, Dietrich, & Angermeyer, 2004).

Family members who are involved with the individual’s life must manage their own personal developmental tasks in corresponding phases of the life cycle, while also planning for the hardships that lay ahead in the unknown future (Rolland, 2005). The fact that families have a history together across generations that includes values and

beliefs adds to the complexity of the interaction among members in the case of chronic illness (Carter & McGoldrick, 2005; Rolland).

Rolland (2005) introduces a time line which incorporates phases of illness to further illuminate the process within the family life cycle. The time line includes three phases: a) crisis, which centers on diagnosis and initial adjustment, b) chronic, implying the “long haul” that must be journeyed by the family, and c) terminal, which focuses on the period preceding death and mourning (p. 498). The periods of time in between each phase are known as critical *transitions*, which can be rather fragile in nature as families work to adapt to the demands to the illness.

Although Rolland (2005) appears to center on physical disabilities to illustrate the model, he explains that each illness characterizes a particular type of onset, whether *acute* or *gradual*, as well as continuing on a unique course known as *progressive*, *constant*, or *relapsing/episodic*. Also, the expected outcome and degree of *incapacitation* or impairment contributes to the effects on family as they anticipate what the future holds for the individual with illness (Rolland). Beliefs and values that families hold, whether through trans-generational means, illness experience, or a combination, will impact the hope that families will have for their loved ones who are chronically ill (Rolland).

As reviewed in the previously cited literature about schizophrenia, it is known that the illness tends to be of the episodic type (Hirsch & Weinberger, 2003; Shean, 2004; Torrey, 2006). Also, the onset of schizophrenia may be sudden, leading quickly to full-blown illness, or gradual with an extended prodromal phase (Hirsch & Weinberger, 2003; Torrey). The outcome of schizophrenia is variable, but usually causes a significant degree

of impairment in multiple areas of daily life (Torrey, 2006). Each of these points is essential to understanding the response of family within the life cycle.

To illustrate points that are relevant to illness life cycles, the following sections will provide an overview of family burden, involvement and separation patterns, and characteristics of parent-adult child relationships.

### **Family burden.**

Families who are met with the diagnosis of schizophrenia will likely be beckoned to sustain family life in the midst of an unpredictable course that will bring forth alternating periods of crisis and stability (Lefley, 1996; Rolland, 2005). This alone has the capacity to cause stress as families work to accept reallocation of role demands, alter adaptation strategies, and respond with flexibility (Rolland). Episodic illnesses such as schizophrenia can be burdensome even during relative stability, when families may be able to carry out their regular routines but will quietly anticipate the next crisis. If the family is incapable of meeting these demands, significant strain occurs which will impact the entire family system (Rolland).

Jungbauer & Angermeyer (2002) distinguish between *acute* versus *chronic* everyday burden. Alternating periods of psychosis and relative stability are characteristic of the course of schizophrenia. Therefore, the resultant effect is a simultaneous oscillation between acute and chronic burden for families who live with mental illness.

The onset of sudden symptoms of psychosis will invariably result in high levels of stress, loss of control, and anxiety for the family (Jungbauer & Angermeyer, 2002).

Acute burden has the tendency to re-appear during episodes of relapse, but some families

may feel more prepared to manage the crisis as they gain experience (Jungbauer & Angermeyer). On the other hand, families may continue to experience chronic burden in times of stability, due to ever present limitations in daily life that may interfere with individuals' personalities, behavior, mood, and general functioning (Jungbauer & Angermeyer).

This concept is further defined in terms of *objective* versus *subjective* burden. Objective burden refers to the observable demands of caregiving which are concrete such as financial dependency, inability to carry out role responsibilities typical of the age cohort, reduced social engagement, unhelpful interactions with health care providers, or disruptive household routines (Jungbauer & Angermeyer, 2002; Lefley, 1996). Subjective burden refers to the family's perception of how disability affects their lives, including the extent to which they feel overwhelmed (Jungbauer & Angermeyer). Dimensions within subjective burden may include mourning loss of premorbid personality, and feelings of depression, anger, burnout, or stigmatization (Lefley, 1996).

Jungbauer, Wittmund, Dietrich, & Angermeyer (2003) studied subjective burden in parents of individuals with schizophrenia over a 12 month period. Through analysis of 47 interview sets with parents, they concluded that parents indeed experienced the simultaneous curve of burden that was associated with illness severity. 40% of parents in the study were described as enduring a constant, high level of burden over the annual period.

Barrowclough & Parle (1997) found that families were most distressed when the adult child's symptoms were more vexing, and when the illness duration was longer.

Sharing a household with an adult son or daughter with severe mental illness often referred to as “resident status,” can increase burden and negative emotional and physical health for family members (Gallagher & Mechanic, 1996; Walton, Gerson, & Rose, 2005). However, families are often still very involved with their loved ones in terms of their financial efforts, time use, and social support even when the individual and family live separately (Lefley, 1996).

In particular, research has uncovered the intense burden on younger parents of adult children in the first several years after diagnosis of schizophrenia, as they work towards accepting this chronic illness and release hopes and dreams they once held for typical adult relationships, marriage, parenthood, and development of a career (Lefley, 1996). In one extensive mixed methods study by Cook, Lefley, Pickett, and Cohler (1994) with more than 200 parent participants, younger parents revealed increased distress as a result of their adult child’s behaviors.

Although obvious gaps are visible in the literature regarding level of burden in the trajectory of family life concerning severe mental illness (Lefley, 1996), some research points to the potential for burden to continue or increase over the course of illness (Cook et al., 1994). Cook et al. suggested that aging parents of individuals with mental illness experience major burden as anxiety mounts in the knowledge that they will not always be there to take care of their mentally ill child. Aging mothers and fathers were also more concerned about emotional involvement necessary for helping their adult child, in contrast to family conflict that seemed to encompass the anxieties of younger parents (Cook et al.). Thus, parents in end of life cycles tend to switch focus toward estate

planning in an attempt to attain more peace with their child's future and their own eventual mortality (Lefley, 1996).

Furthermore, the study also suggested that minority parents who had less education were more preoccupied with the responsibility they had for their adult child (Cook et al., 1994). This, the authors note, was in contrast to other studies that point to Caucasian parents as having higher levels of burden, particularly surrounding issues of behavior management. Most studies have suggested that Caucasian parents are carriers of higher burden, in addition to relying more on professionals for support (Carpentier, 2006). Families of ethnic minority have provided informal care at home to their relatives with mental illness for longer periods of time, expressed less burden of care, and relied less on professionals to assist them (Carpentier).

As typical developmental tasks are derailed by mental illness, families are left to become entangled in the aftermath. Families are aware that their loved ones are isolated from regular social activities and behave differently than they once did (Rose, 1998). As caregivers, many families attempt to make sense of the new personality that emerges with mental illness, concerned that they will perhaps never see the person in their former self again (Rose).

Some families may be successful in accepting the person with illness, but others continue to question whether anything positive remains (Rose, 1998). Instead, many families may only be able to focus on the sense of loss and ruin associated with the mental illness. One family in a study by Rose shared a private internal dialogue: "In the back of my mind, I knew that a schizophrenic doesn't get better..." (p. 367).

Tuck, du Mont, Evans, & Shupe (1997) studied the experiences of key family members who cared for adult children with schizophrenia using phenomenological methodology. Their analysis suggests that family members experienced the illness as a destructive force, disrupting and transforming the typical course of family life. Furthermore, families grieved over the loss of their imagined child and the realization of the present child as a “needy stranger” who could not be depended upon to make sensible life choices (p. 123). Families in this study occasionally revealed glimpses of the former child they once knew, which tended to allow hope to take hold in their thought processes. It is family experiences such as these that inform us about possible barriers in supporting individual recovery efforts (Lefley, 1997).

Families often experience judgments by the public and providers themselves, contributing to the problem of family stigma (Larson & Corrigan, 2008). They often feel that they are blamed for their relative’s mental illness and as a result, tend to avoid some social situations and attempt to hide the secret (Larson & Corrigan). In terms of provider relationships, families have identified themes of powerlessness, isolation, desire for partnership, and a need to be recognized and valued (Pejlert, 2001; Wilkinson & McAndrew, 2008). This may only be magnified by the ever present focus on families as contributors to relapse (Brekke & Mathieson, 1995).

In addition to emotional burden experienced by family members, it is important to note that physical burden can ensue as well (Gallagher & Mechanic, 1996). Living with a person who has severe mental illness has been found to be a contributor to poorer physical health, limitations in activity, and increased use of health care services (Gallagher & Mechanic).

Finally, although a number of studies have revealed the burden on families living with mental illness, care giving is not always seen as negative. Some studies have highlighted the positive aspects of care giving roles, and the contributions of ill family members to the household (Greenberg, Greenley, & Benedict, 1994).

### **Family involvement and separation patterns.**

Families are involved with their relatives who are mentally ill in a myriad of ways (Carpentier, 2006; Chrzastowski, 2007; Jungbauer et al., 2004). Remarkably, few studies are available to describe family involvement in depth (Brekke & Mathiesen, 1995; Carpentier). As Carpentier (2006) suggests, the extent of family involvement can be seen as positive, but it has also been cited as a contributor to dysfunctional patterns. In one mixed methods research study with consumer and family participants, four types of family involvement were uncovered over the course of severe mental illness (Carpentier).

Carpentier (2006) found that just under one third of the consumer participants lived with family members, with the family being involved on a daily basis on all levels. Just over one third of consumers left home to live more independently, but families were still heavily involved. Some families, however, found that it was too difficult to remain involved, but still hoped for recovery for their loved one. And lastly, one subset of parents had broken off contact with their relative while dealing with conflicts in the family such as divorce, or economic hardships such as the loss of employment. One important area of discussion that ensued as a result of this study was that research studies are lacking in the discovery of how families orient their strategies and define their obligations and levels of responsibility with their mentally ill relatives (Carpentier).

Given the substantial impact of mental illness on the family, it is not unusual for families to experience difficulty in separating from adult children as they attempt to meet the intense needs of their relatives (Carpentier, 2006; Jungbauer et al., 2004). Parents, in particular, may experience intense *binding*, exemplified by over protectiveness, guilt, separation anxiety, and over-involvement (Chrzastowski, 2007). On the other end of the spectrum, parents may *expel*, or demonstrate more critical attitudes toward their adult children with schizophrenia, creating more emotional distance in the relationship (Chrzastowski). In this way, they may tend more towards isolating the mentally ill family member (Carpentier). Notably, separation patterns may indeed change over the course of illness (Chrzastowski).

Families may also differ in cultural tendencies toward individual versus collective orientations to care taking tasks (Carpentier, 2006; Lefley, 1997). For example, American cultures tend toward an individualized view of caring for relatives, feeling freer to delegate care taking to others such as professionals (Carpentier; Lefley, 1997). In contrast, non-western cultures more readily support collective, community views of care taking. Therefore, individuals in these cultures can acceptably rely on family members to support them through provision of practical and emotional support (Carpentier; Lefley, 1997).

These cultural influences, among other personal and environmental features, play a role in how families may become involved and stay involved in the care of relatives with mental illness (Carpentier, 2006; Lefley, 1997). A study by Karp and Watts-Roy (as cited in Carpentier) revealed that care givers felt especially obligated to provide care at the onset of mental illness, but that initial motivations faded through the course of illness.

The study described parents' perspectives of this ostensible change in devotion towards care giving. Parents explained that their abilities to persevere in care giving decreased if they felt "their efforts to care were ineffective, their own health was seriously jeopardized, or their sense of identity was in danger of obliteration" (p. 34). This study highlights the potential layers of intricacy associated with family involvement.

### **Parent-adult child relationships.**

Though much research exists on the issue of caregiver burden, the literature is lacking in the focus on family experiences and relationships in the case of schizophrenia (Jungbauer & Angermeyer, 2002). When considering family relationships of young adults with schizophrenia, it is important to recognize who may be most involved in their lives at the relevant developmental stage. As young adults transitioning from adolescence, the most likely source of support would be parents, which is the main area of literature review for this dissertation study.

Typically, parents in the launching children phase would be involved with letting go of their adult children, thereby creating a larger, more moveable boundary between members (Blacker, 2005). Instead of the heavy laden tasks of child-rearing, families would normally be focusing on greater independence for adult children (Blacker). Parents may be in the process of exploring other life goals and increasingly permitting adult children to begin making their own way in life (Blacker).

With the onset of illness, however, parents tend to enter an untimely transition back to an enmeshed child-rearing phase (Rolland, 2005). Through the individual's loss of ability to fulfill expected responsibilities and roles in his or her young adult life, so the

family must grieve the loss as well (Lefley, 1996). Parents of mentally ill adult children must endure an assortment of emotions related to the letting go of ideals they had held for their children as they are catapulted into a new life with mental illness (Rose, 1998; Lefley, 1996). In response to the intense needs of their adult children, the parental response may be an increase in cohesion as the family is further socialized to this chronic illness (Rolland). This has been described previously as separation.

Whereas it is not atypical for parents of healthy adult children to experience a temporary return of their adult children after college, parents of adult children with schizophrenia face the real possibility of a permanent, lifelong return to parenting (Jungbauer et al., 2004; Wasow, 1995). The life cycle transition of launching children into independence is not realized in the case of severe mental illnesses like schizophrenia. Parents of adult children with mental illness, find that their children remain dependent upon them for support as they lose other social contacts to the difficulties posed by the illness (Jungbauer et al.). In these ways, family relationships become more intense (Jungbauer et al.).

Because adult mentally ill children are often dependent on their parents for support at an unexpected time of the life cycle, individuals with illness are often frustrated, guilty, and resentful over the fact that they need this level of support (Lefley, 1996). Parents often become the obvious scapegoat for intense feelings of inadequacy on the part of the person with illness, sometimes becoming targets for verbal and physical acts of rage (Estroff et al., 1994). Mothers have been cited as particularly vulnerable to the problem of violence in their supportive roles (Lefley, 1996).

A study by Bornstein and O'Neill (as cited in Lefley, 1996) found that parents of adult psychiatric patients revealed more negative perceptions of their children than did parents of non-psychiatric adult children. In addition, this study revealed that adult mentally ill children displayed less recognition of their parents as individuals with a multiplex of qualities and emotions. Instead, they tended to view their parents as bearers of gratification or of frustration. In addition, adult children with mental illness displayed more ambivalence toward their parents when compared with non-psychiatric controls.

### **Family and Medication Adherence**

Through a number of mixed reviews, family support has been inconsistently cited as influential to medication adherence for people with schizophrenia (Bebbington, 1995; McCann, Clark, & Lu, 2008; Pyne et al., 2006). For example, Santone et al. (2008) found that families played a predominant role in the negative attitudes toward medications held by the person who is ill. Of course, families interact with their loved ones' in a number of ways, as each relationship is unique. It is understood that some families are involved, some are more distant, and yet others are seen as over-involved with high expressed emotion (Jungbauer et al., 2004; Pyne et al., 2006; Sellwood, Tarrier, Quinn, & Barrowclough, 2003). These factors conceivably play a complex role in consumer and family interactions around medications.

Since many people with schizophrenia live at home, family members are potentially significant influences in medication decisions, adherence, and the recovery process (Bebbington, 1995; Brady & McCain, 2004; Lefley, 1997). As the family works to sustain a semblance of routine life in the face of illness, medication non-adherence may add fuel to the fire. As psychotic and cognitive symptoms worsen, families may

experience further disruption of life in the shadows of a potential crisis (Jungbauer & Angermeyer, 2002). Families who have experienced non-adherence episodes in the past may begin to anticipate the onset of psychosis before it actually occurs (Jungbauer & Angermeyer).

Because medications are so often rejected by individuals with schizophrenia, families must bear the brunt of the accelerated psychosis that may ensue (Lefley, 1997). Families have been targets for violence at times, perhaps more so when living in the same household (Estroff et al., 1994; Lefley, 1997). It is possible that individuals with schizophrenia may develop paranoid thoughts about their family members, particularly when families feel it necessary to impose limit setting on behaviors (Lefley, 1997).

It is also likely, as reviewed within the life cycle literature, that young adults with this illness would experience intense feelings of inadequacy in their inability to fulfill the typical developmental roles and tasks expected of them by their families and society as a whole (Lefley, 1997). Families can plausibly become a symbol of the ill family member's insufferable limitations in life, which can result in displaced anger (Lefley, 1997).

Also, hypersensitivity to perceived threats, a possible symptom of schizophrenia, could also contribute to ensuing family conflicts (Lefley, 1997). Similarly, medications themselves can become an object of this type of symbolism (Lefley, 1997). Considering the family's likely support of medications and their frustrations with medication non-adherence, it becomes easy to imagine what pain, anger, and conflict may result among family members.

Individuals with schizophrenia may struggle with the sense that they have not lived up to expectations of their families, and therefore may not feel supported. Lefley (1996) proposes that rejection of medication may be one way for the mentally ill person to gain more power and control, a potential form of pay-back for the family's belief that he or she cannot get well without treatment. Therefore, she proposes that adamant refusal of medications may stem partly from the ill member's need to disconnect from the perception that they may be the source of family conflicts.

In an Australian study by Rudge and Morse (2004), families identified ambivalent feelings toward medication use for their loved ones with schizophrenia. On one hand, families revealed that medications were a source of constant anxiety and a last resort, serving as evidence that their loved one was indeed mentally ill. By the same token, they feared the moment when their loved ones would stop taking medications. Also, families in this study expressed frustration at their attempts to make an appointment with the psychiatrist in order to modify medications, and therefore, resorted to self-adjustment of medication dosages.

This leads to a description of a common ethical dilemma in families, which is that of covert delivery of medications in beverages or drinks (Wong, Poon, & Hui, 2005). In essence, this practice has been used by families in cases where individuals are questionably competent to decide for themselves, or perhaps when psychosis is severe. It is often justified as ethical by families and some mental health systems when essential treatment would be in the person's best interest (Wong, Poon, & Hui). Families, who feel desperate and unsupported by providers, may feel they need to resort to this action to

restore order and safety to the family (Wilkinson & McAndrew, 2008; Wong, Poon, & Hui). However, covert medication delivery remains highly controversial.

### **Families as Social Support**

Since most of the literature tends to focus on family as etiology and on particular issues relative to caregiver burden, less is understood about how families serve as supports to relatives who are mentally ill (Brekke & Mathiesen, 1985; Lefley, 1997; Lefley, 1998). The types of relationships individuals with illness have with their social supports would seem to be a key area of inquiry in the quest toward mental health recovery. After all, recovery is said to be more than an individual pursuit (Glynn, Cohen, Dixon, & Niv, 2006; Hendryx, Green, & Perrin, 2009; Schon, Denhov, & Topor, 2009; Topor, Borg, Di Girolamo, & Davidson, 2009).

Social relationships play a key role in recovery processes (Schon, Denhov, & Topor, 2009). However, few studies have focused on which characteristics are attributed as priorities in social relationships (Breier & Strauss, 1984). Furthermore, the effects of social relationships on the course of illness, or how needs may shift in the process is not well-understood (Breier & Strauss).

Breier and Strauss (1984) conducted one such study using qualitative methodology with 20 individuals with psychosis in the hospital and again 1 year post-discharge. Individuals identified 12 functions that were helpful within the context of social relationships that included: a) *ventilation* (act of conversing with others and expressing emotions), b) *reality testing* (distinguish boundaries of reality and delusions), c) *material support* (financial and housing), d) *social approval and integration* (accepted

versus ostracized for the illness), e) *constancy* (contact with people they knew before hospitalization to remind them they were once sane), f) *motivation* (expect higher social and occupational function), g) *modeling* (observed others' examples and incorporate into own behavior), h) *symptom monitoring* (observing for manifestations of illness), i) *problem solving* (getting feedback and working out issues), j) *empathic understanding* (others understand illness and accept), k) *reciprocal relating* (sharing and assisting other people increased sense of personal value), and l) *insight* (more complete and accurate understanding of self).

Another helpful study by Rose (1998) centered on family relations in mental illness. Her study was based on the theory of symbolic interactionism, whereby meanings are constructed through the process of reciprocal relating among the caregiver and individual with illness (Rose). Through analysis of qualitative data, three themes were suggested to represent meanings associated with care giving which included: a) the family's search for ways to stay connected with the ill member, b) ways the family influences the ill member with words, actions, and presence, and c) ways that family helped the ill member to move forward, whether that involved "stepping back" or "stepping in" (p. 367). In addition, caregivers noted that meanings were not constant, but changed over time.

Families in this study also discussed their need to develop routines in order to gain control over issues such as making the individual upset (Rose, 1998). They admitted that finding a routine that finally worked for the family only came after a number of trials and errors. They also described the need to ignore symptoms because they did not want to invite trouble or cause a commotion within the family. Similarly, families chose their

words wisely so as to keep the peace in the family, sensing that their words had the power to make the individual better or worse in terms of illness symptoms (Rose).

These findings are significant to this proposed study in that family members may feel a need to ignore signs of relapse and retreat verbally when faced with medication adherence dilemmas, primarily to avoid disruption in the family unit. Certainly, avoidance of “rocking the boat” can be assumed as a measure of homeostasis, a way to maintain or gain control of unpredictability inherent in life with mental illness. Furthermore, if individuals find certain benefits to social relationships, such as the ability to problem-solve or ventilate concerns, this may conceivably inform issues related to medication adherence.

### **Person-Environment-Occupation Model**

The Person-Environment-Occupation Model (PEO) is a comprehensive tool that can be used to classify the activity of medication adherence using terminology that resonates within occupational therapy, but is also conceivable to other psychiatric disciplines. The model was developed by a Canadian occupational therapist, Mary Law, along with her colleagues for the purpose of illustrating the transactional relationship between person, environment, and occupation (Law et al., 1996; Rigby & Letts, 2003).

The authors proposed that occupational therapy, with its specialized knowledge about these three components, could provide valuable knowledge to the body of literature existing in various disciplines such as psychology, anthropology, and sociology (Law et al., 1996). Furthermore, the outcome of transaction between person, environment, and occupation is *occupational performance* (medication adherence), an area of expertise for

occupational therapists as they routinely work to engage clients in meaningful, fulfilling life activities.

Law and her colleagues (1996) emphasize that behaviors cannot be completely separated from the contextual influences of the environment, the task demands of the occupation, and the personal characteristics of the client. Therefore, a transactive approach is proposed, along with the developmental view of a person as he moves through the lifespan (Law et al.).

The model emphasizes the dynamic, temporal aspects of occupational roles and routines that change over time and continually through life (Law et al., 1996). The interaction between the three major components either creates *fit* or *lack of fit*, which minimizes or maximizes the outcome of occupational performance. When the overlap between components is closer, it is assumed that they are working more compatibly with one another. Alternatively, when less overlap occurs, occupational performance is decreased (Law et al.).

The model assumes that a person is motivated and always changing while performing occupations and interacting with the environment (Law et al, 1996). A person is composed of mind, body, and spirit and is influenced by life experiences that have shaped who he is, inclusive of his personality, competencies, self-concept, and culture. Competencies contain information about ones abilities, with consideration to the experience of the particular health condition (Law et al.).

The environment is broadly defined within the PEO Model and includes cultural, socio-economic, institutional, physical, and social components (Law et al., 1996; Rigby

& Letts, 2003). Each of these components is given equal weight in level of importance. All domains are viewed from a micro to macro level from the standpoints of person, household, neighborhood, and community (Rigby & Letts).

The environment impacts behavior in the sense that contexts contain cues that influence human response (Law et al., 1996; Rigby & Letts, 2003). Conversely, individuals' behaviors also impact the environment. The environment, dynamic and changing, is understood to be more yielding to change than person components. Intervention by occupational therapists targets change in the environment in order to optimize the PEO fit, thereby improving occupational performance (Law et al.; Rigby & Letts).

The PEO Model defines occupations as “clusters of activities and tasks in which the person engages in order to meet his or her intrinsic needs for self-maintenance, expression, and fulfillment” (Law et al., 1996, p.16). Over the lifespan, people carry out meaningful occupations within the context of personal roles and within a variety of environments. Concepts such as activity and task are seen as nesting together with occupation (Law et al.).

### **Recovery Model for Mental Illness**

*“I don't let my illness run me...Being in recovery means I don't just take medications, rather I use medications as part of my recovery process”* (Deegan, 1993, p. 10).

Although a variety of perspectives have been used to explain medication adherence, the recovery model in mental health is one that holds promise for understanding the issue against the larger premise of living with severe and persistent

mental illness. After all, there is no point to viewing medication adherence in isolation of other important influences in the lives of human beings. As previously discussed, many studies have already concluded that medication adherence is complex, multi-layered, non-linear, and not unique to individuals with schizophrenia (Marland & Cash, 2005; Rogers et al., 1998). Furthermore, as will be discussed in the upcoming review of the literature, the recovery model reflects the experiences and desires of individuals with mental illness, from the perspective of the person who is living it each day.

As the quotation above implies, consumers may need to integrate medications into their own recovery processes, creating meanings for the ways in which they find to manage their lives. For some, medications may be one of many mechanisms to assist in the work of recovery. For others, medications may serve as a reminder of the illness that overwhelms their life. This dissertation study may shed light on how the individuals in each of the case studies view their medications, against the backdrop of everyday life with schizophrenia.

## **Background**

Perspectives on recovery were born of the Civil Rights and Independent Living Movements, emphasizing that people have a right to continue their lives despite the fact that symptoms of illness may remain (Anthony, 1993; Davidson & Roe, 2007; Jacobson & Greenley, 2001). Literature on recovery began appearing in the 1980's, infused with perspectives of consumers who considered themselves to be in the process of rebuilding meaningful lives despite the presence of chronic illness (Deegan, 2005; Mead & Copeland, 2000). A number of factors helped to establish the means that finally set the stage for consumers to express their views about mental illness and recovery including

deinstitutionalization, community psychosocial mental health program development, and the surfacing of grassroots organizations such as the National Alliance on Mental Illness (Anthony).

Recovery has gained global interest in recent years, advancing to the forefront of mental health policies and legislation (Davidson & Roe, 2007; Lieberman et al., 2008). In 2002, The President's New Freedom Commission on Mental Health was established, which promoted recovery as the primary goal for individuals with mental illness (Lieberman et al.). An impetus to study recovery from schizophrenia has been suggested in order to provide empirical evidence that validate its concepts (Lieberman & Kopelowicz, 2002). Currently, research on recovery is in the beginning stages, and definitions of recovery are continually unearthed from the perspectives of consumers and families (Lefley, 1997).

### **Recovery Defined**

Recovery has been described in countless ways (Jacobson & Greenley, 2005; Lieberman et al., 2008). Many would believe that recovery from an illness is equivalent to cure, or a complete cessation of symptoms. However, a shift in philosophy has brought forth a vision of recovery as an ability to move forward with life as opposed to waiting for a cure (Lieberman et al., 2008; Lysaker & Buck, 2006). Instead of a life once thought to be an imprisonment of sorts, lost in a sea of illness (Barham & Hayward, 1998; Roe et al., 2008), recovery emphasizes the resilience of the human spirit to begin again (Deegan, 2005).

Although recovery includes broad concepts such as quality of life, it also describes individuals' capacity for self-agency, hope, resilience, active involvement with treatment, managing daily life, following dreams, and pursuing meaningful goals (Deegan, 2005; Lieberman et al.; Noh, Choe, & Yang, 2008). Recovery is regarded as both an outcome and a process (Corrigan, 2006; Lieberman et al., 2008).

Davidson and Roe (2007) offer a definition of recovery *in* illness versus *from* illness. Whereas recovery from illness implies a cure or reduction of symptoms, recovery in illness refers to *how* the person lives with it. Recovery *in* illness highlights the role of the person with mental illness as agent of his or her own life, adapting to reduce the impact of the illness while simultaneously building on personal assets (Davidson & Roe).

The idea of recovery as a social process has been described in numerous studies (Anthony, 1993; Borg & Davidson, 2008; Davidson et al., 2009; Hendryx, Green, & Perrin, 2009; Jacobson & Greenley, 2001; Schon, Denhov, & Tapor, 2009; Topor et al., 2009). Social process refers to the concept of being supported by others (Davidson et al., 2009). A variety of others may serve in support roles such as family members, friends, peers, providers, and even animals (Davidson et al.).

Social process in recovery is deemed critical by individuals with mental illness, as they have communicated the importance of having others who encourage, celebrate, and believe in them (Anthony, 1993; Davidson et al., 2009). Furthermore, Borg and Davidson (2008) identify recovery as a social process that occurs in the simple everyday life activities such as eating meals or celebrating birthdays. Everyday activity is often overlooked as part of the recovery process, "invisible precisely because it is too visible"

(Borg & Davidson, p. 2). Jenkins and Carpenter-Song (2005) also discovered that participants with schizophrenia frequently recognized the dimension of ordinary activities in their visions of personal recovery.

### **Recovery: Is it for Real?**

Is recovery more than new wine in an old bottle (Bellack, 2006)? Is it really anything more than the power of positive thinking (Torrey, 2006)? Can recovery successfully enter into the equation of practice that currently operates under medical model paradigms?

Some researchers, such as Torrey (2006) question recovery for a few reasons. First, Torrey wonders if too many expectations are placed on consumers to recover in the face of many serious barriers related to their illness. This, he adds, is not helpful to consumers because it potentially intensifies stress. Also, he cites the lack of foundation set forth by scientific studies.

But Davidson et al. (2009) have dedicated a recent book to incorporating research on recovery into clinical practice, proposing incentives and strategies to transform mental health practice as we know it. One of the strongest arguments for recovery has been research findings that suggest more individuals recover than do not (Carpentier, 2006; Davidson et al.). This stands in stark contrast to notions of chronicity and imprisonment by mental illness. Whereas individuals may have been told by their physicians that there is little to no chance for improvement, even with medications, it is now recognized that hope is on the horizon for a better life. It has been estimated that at least half of

individuals with schizophrenia will achieve recovery, in the sense that improvement occurs (Bellack, 2006; Carpentier; Davidson et al.).

One study by Jenkins and Carpenter-Song (2005) used qualitative methodology to determine individuals' subjective experiences of recovery. 90 participants with schizophrenia-related disorders revealed that recovery was connected with low levels of symptoms, the need to take medications in order to evade hospitalization or relapse, and their personal ability for self-agency in the face of illness effects.

Remarkably, individuals in this study described a “catch-22” conflict involving use of medications, as they struggled with the decision to “be fat” or “be crazy” (Jenkins & Carpenter-Song, 2005, p. 380). They also revealed that personal control in their efforts toward recovery was necessary, and that medications were not exclusively responsible for recovery. Sustaining this type of personal effort toward recovery was found to be linked with social engagement. Furthermore, social support was conceptualized to be a reciprocal, “giving and receiving” process between individuals and their supports (Jenkins & Carpenter-Song, p. 407).

### **Integration of PEO and Recovery Models**

Despite lack of a concise framework, the recovery model offers a number of perspectives that is helpful to inform the issue of medication adherence. The PEO Model is a fitting method to conceptually organize concepts of recovery within its broad components of person, environment, and occupation. Although the PEO Model can certainly stand alone in its principles and assumptions, recovery concepts complement each component to further enhance understanding of the issue of medication adherence

for individuals with schizophrenia. Furthermore, recovery has been said to complement principles of occupational therapy (Merryman & Riegel, 2007).

One of the overarching perspectives that both models share, is the view of human beings as dynamic and constantly changing along with their environments. Therefore, where human beings are concerned, linear relationships do not truly exist. However, the extraction of concepts in dynamic processes is admittedly complex (Lieberman & Kopelowicz, 2002). This researcher, after thorough review of each model in previous doctoral coursework, has adapted the models in such a way that concepts are nested within one another (*Figure 1*).

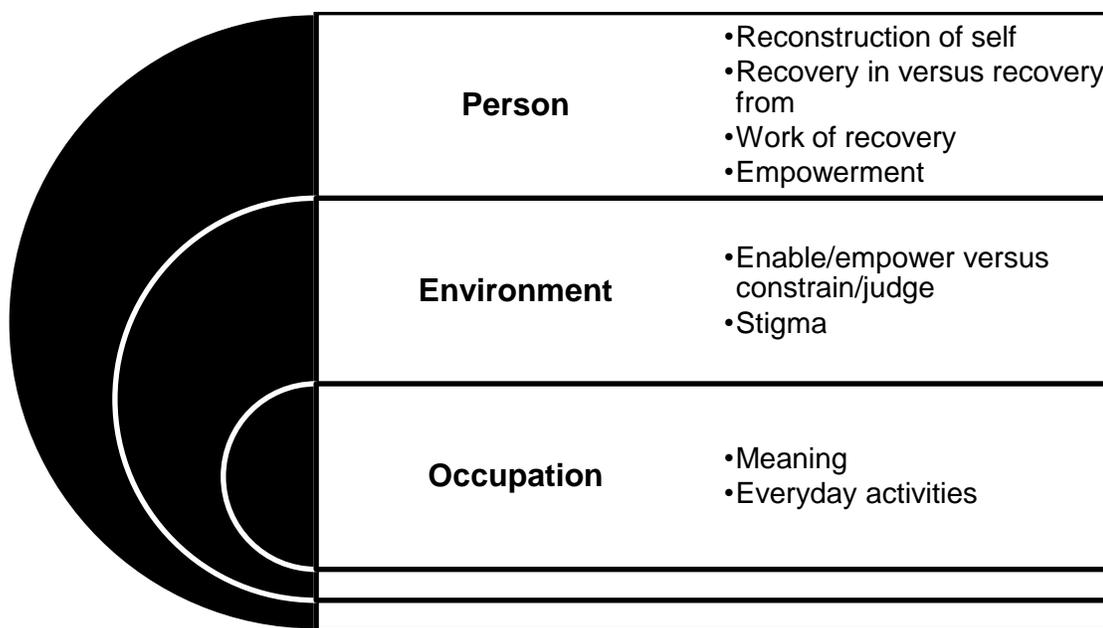


Figure 1: Merger of PEO and Recovery Models

As seen in Figure 1, examples of personal features that potentially merge with recovery include reconstruction of self, recovery in versus recovery from illness, and the work of recovery. Within the environment component, recovery concepts that

complement the PEO Model as part of social and institutional environments may include the ability of others to enable and empower individuals (versus constrain and judge), and the impact of stigma. Concepts of recovery that fit into the PEO component of occupation could include meaning related to medication use as well as the concept of everyday activities as constituting recovery.

Harmonizing concepts emerge in the blending of both models, proposing a welcomed joining of PEO and recovery for the purpose of discourse surrounding medication adherence. Notably, PEO and recovery potentially unite in a variety of other ways beyond the examples shown. This dissertation study may shed light on new dimensions in which to consider. For the purposes of illustrating a few examples of how the models may blend to inform medication adherence, the following section will further discern aspects of each component of PEO and recovery as it relates to medication adherence.

### **Person and Recovery**

The person, the self, can be clearly interwoven between the PEO and recovery models. The person component of PEO is amalgamated with concepts from recovery such as reconstruction of self, recovery in versus from illness, the work of recovery, and empowerment/perceived control (Bonney & Stickley, 2008; Davidson & Roe, 2007; Davidson & Strauss, 1992; Eklund & Backstrom, 2006; Jenkins & Carpenter-Song, 2005; Law et al., 1996; Liberman & Kopelowicz, 2002; Lysaker & Buck, 2006; Noordsy et al., 2002; Pettie & Triolo, 1999; Spaniol, Wewiorski, Gagne, & Anthony, 2002; Strauss, 2008; Strauss, 1994).

Within the PEO Model, the person is seen holistically encompassing mind, body, and spirit (Law et al., 1996). Each person possesses a set of characteristics and experiences that affect the outcome of occupational performance, in this case medication adherence. Personality, cultural background, personal competencies, and self-concept are traits that each person brings to the transaction with the environment and occupation. Because the relationship is transactive, one can only separate these components to a degree for organizational purposes. The person cannot be completely divided from the impact of environment and occupation.

Building on PEO concepts, recovery literature suggests that people with mental illnesses may be faced with significant trials in regards to self-concept, possibly necessitating re-definition or reconstruction of who they are (Bonney & Stickley, 2008; Davidson & Strauss, 1992; Pettie & Triolo, 1999). Jenkins and Carpenter-Song (2005) have also emphasized sense of self as significant in the recovery process of mental illness.

Self-awareness changes over time as individuals begin to perceive separate versions of themselves (Pettie & Triolo, 1999). That is, individuals compare who they were in the past and who they have become in the advent of mental illness. The former self is usually idealized as healthy and successful, whereas, the current self is seen as “unsuccessful, sick, weird, or worse” (Pettie & Triolo, p. 256).

As individuals in recovery, reconstructing self is a part of learning how to live with illness and develop a meaningful life despite symptoms (Davidson & Roe, 2007;

Pettie & Triolo, 1999). As discussed previously, this concept is explained by Davidson and Roe (2007), in their comparison of recovery *in* versus recovery *from* illness.

A cure is not the expected outcome of individuals in recovery, but a life that validates identity, hope, and a future of possibilities (Davidson & Roe, 2007; Liberman & Kopelowicz, 2002; Pettie & Triolo, 1999). Though individuals may struggle with identity after illness, they are capable of learning how to live with illness as agents of their own health. Individuals with mental illness have the capacity for resilience (Deegan, 2005) and have not been entirely lost to their illness (Barham & Hayward, 1998; Davidhizar 1985; Roe et al., 2008).

As individuals work toward rebuilding their lives under the precept of a new normal, their relationships with medications are apt to change throughout the process. This concept of changing relationships is presumably enfolded within the idea of people as dynamic systems, and illuminates the process of transformation throughout the lifespan. Karp's (2006) description of issues related to self-identity and medication adherence for individuals suffering from depression, as described previously in this literature review, is also an example of the intersection between self factors and medication adherence.

Davidson and Roe (2007) highlight the role of a person with mental illness in the active pursuance of recovery. Engaging in the active work of recovery implies that a person is working towards living their life in a way that is meaningful and dignifying, in settings of their choice, despite the presence of illness. Evidence of recovery is unique to each individual and tied to personal goals (Liberman & Kopelowicz, 2002).

However, according to Davidson and Roe (2007), everyone with mental illness is not necessarily in recovery. Instead, they raise a provocative question about what people may be doing if they are not thought to be implementing the active work of recovery. A few possibilities are proposed: a) individuals have not yet made a distinction between illness and effects on their lives, b) the severity of the illness is overwhelming their abilities to cope, or c) some people will choose not to manage their illnesses (p. 468). Additionally, Strauss (1994) proposes the possibility of a person with illness reaching a plateau in their recovery, which he terms *woodshedding*. This has been further conceptualized by Pettie and Triolo (1999) as reaching a state of limbo.

### **Environment and Recovery**

Both the PEO and recovery models support the importance of the environment, though from unique perspectives. The PEO Model broadly defines the concept of environment, applying equal consideration to physical, cultural, socio-economic, institutional, and social aspects (Law et al., 1996). Again, the environment is an integral part of the transactive relationship of person and occupation. The environment is a component that can either constrain or enable people to participate in occupations (Rigby & Letts, 2003). Consideration of environmental influences on health is consistent with objectives identified by those in the Independent Living Movement (ILM) and the World Health Organization (Letts, Rigby, & Stewart, 2003).

The recovery model implies the importance of the social environment, without use of this explicit terminology. Parts of the social environment that are frequently discussed in terms of recovery include the impacts of therapeutic relationships between professionals and clients, beliefs among caregivers that limit or enable recovery, as well

as the impact of societal and self stigma (Corrigan, 2006; Deegan, 1996; Noordsy et al., 2002; Spaniol, Wewiorski, Gagne, & Anthony, 2002).

Environmental concepts that span both models include the presence of social supports that enable and empower individuals versus constrain and judge, as well as the impact of societal stigma (Brady & McCain, 2004; Deegan, 2005; Deegan, 1996; Law et al., 1996; Lieberman et al., 2008; MacPherson, 2009; Mortenson & Dyck, 2006; Noh, Choe, & Yang, 2008).

The institutional and social environments are perhaps the concepts most shared between the models, and are addressed in this literature review. According to PEO, the support of health providers and families are considered part of the institutional and social environments (Law et al., 1996). Any and all of these characteristics can serve to influence the performance of medication taking, shaping the fit between person, environment, and occupation (Law et al., 1996; Law, 1991; Rigby & Letts, 2003).

### **Institutional.**

Therapeutic alliance between providers and clients involves collaboration, trust, listening, belief, hope, caring, risk-taking, and a focus on the client's self-agency and resilience (Clark & Bell, 2000; Deegan, 1996). These characteristics are altogether significant to the idea of client-centered care; a notion embraced by the occupational therapy profession as well as other health disciplines (McCormack & McCance, 2006; Sumsion & Law, 2006).

The spirit of client-centered care is summed up as a collaborative relationship between clinician and client, empowering clients to actively negotiate their own goals,

solve their own problems, participate in meaningful occupations, and fulfill their life roles (Sumsion & Law; Townsend, 2003). In true collaborative communication, clients are given the opportunity to voice their experiences without interruption or excessive attempts by providers to interpret their comments. Vital and meaningful connections are created when a shared interaction is respected between therapist and client (Fearing, 2000).

Barriers to following through with client-centered care include the emotional presence of the clinician, readiness to listen to clients' perspectives, institutional bureaucracy, promotion of scientific/ biomedical approaches, views about chronicity of schizophrenia, and beliefs about the abilities of clients to take leadership of their own health care (Deegan, 1996; Fearing, 2000; Mattingly & Fleming, 1994).

As a result, clients with mental illness can be described as feeling disempowered, marginalized, and helpless in the treatment process (Mortenson & Dyck, 2006). Clinicians' tendencies to harshly judge, or apply labels such as "unmotivated" or "non-compliant" inevitably lead to mistrust and obstruction of self-expression (Fearing, 2000). Considering medication adherence, clinicians may have a tendency to embrace their own value systems, exchanging true listening for a persuasive argument.

The medical model is notoriously expert-driven, placing the provider in a position of power and client as subordinate (Townsend, 2003). Regarding medication adherence, it is not unusual for providers to expect clients to follow their advice. In many ways, the medical model is in direct opposition to the ideas of recovery, including that of self-agency.

Noordsy et al. (2000) review principles of biological, rehabilitative, and recovery models in the management of antipsychotic treatment. Although the authors of this review admit that psychopharmacology under the recovery model is not well-defined yet, they propose some ideas for integrating concepts.

One primary suggestion is to provide hopefulness to individuals who are asked to take medications. That is, to carefully consider and reframe negative prognosis statements toward efforts to improve medication, functional outcomes, and realistic hope for a cure. Also, prescribers can refrain from “subtle coercion” to take medications and make efforts to support skills necessary for recovery, including the skill of managing their personal health (Noordsy et al., 2000, p. 26).

In addition, the authors suggest a decision-making approach to medications that involves shared partnerships between patients and prescribers (Noordsy et al., 2000). As challenging as it may prove to assimilate models of care, individuals with mental illness are expected to benefit greatly from the effort. Although this proposed study will not include the perspectives of mental health providers, this may be a worthwhile future endeavor.

### **Social.**

The family is another significant social environmental influence with the power to constrain or enable occupational performance. This has been thoroughly addressed in the family literature section of this review. However, it is worthwhile here to address some pertinent concepts, limited though they may be, to the experiences of family in the mental health recovery process of their relatives.

In a review of family and recovery literature, Lefley (1997) asks the important question of whether or not the ideas surrounding consumer recovery will help to ease family burden. As families are most closely entangled within one another's lives and certainly throughout the course of severe mental illness, it is fitting to propose this question. Given the frustrations of the individual with schizophrenia in the quest to live a fulfilling life, and the conflicts that occur within family relationships, she proposes that recovery could be a helpful vision for all involved.

For example, empowerment in the sense that one can move toward rebuilding a meaningful life may theoretically equate to less anger and feelings of inadequacy on the part of the individual who is mentally ill. The person who is mentally ill could become easier to live with, perhaps able to focus less on need gratification and accusatory behaviors toward families and more on the accomplishment of autonomous goals. Also, the individual's regained sense of hope and self-determination could lead to a new independent living situation outside of the original family's home, freeing family members to pursue their own goals and interests (Lefley, 1997).

One possibility that supports a recovery vision for taking medications is that medications serve as a supportive tool in the quest for an improved life. On the other hand, medications in the context of recovery may not be perceived as necessary for rebuilding a meaningful life (Roe et al., 2009). It then becomes pertinent to consider whether burden on families could potentially increase as a result of the recovery vision in the case that autonomy may lead to non-adherent behaviors. By the same token, it is possible that families' support of recovery in the life of their loved one may in fact depend on the level of their burden.

Also significant to this issue is the level of dysfunction that differs so greatly among individuals with schizophrenia (Lefley, 1997). Relatives of individuals with severe symptoms and resultant functional impairments may not be able to acknowledge a recovery vision for their family members. This is conceivable when, in the family's view, individuals may not seem to be aware of their own illness or capable of doing what is necessary for recovery (Lefley, 1997).

### **Socioeconomic and policy.**

Economically speaking, if individuals with schizophrenia do not commence poor they usually wind up poor due to the enormous costs of medical care, including medications (Blackwell, 1997). The economic impact on families is substantial and documented as a primary source of caregiver burden (Koukia & Madianos, 2005). Individuals will typically require public insurance within the course of their illness as they are too disabled for employment, and funds have a tendency to empty quickly. The process to acquire social security income or social security disability income is a lengthy and complicated process sometimes fraught with appeals, which is exasperating for people with schizophrenia. Applying for public health insurance programs such as Medicaid is equally taxing for individuals and families.

Health insurance policies often discourage medication adherence by utilizing restricted formularies and requiring fail-first strategies (Duckworth & Fitzpatrick, 2008). In fact, a study by Soumerai et al. (as cited in Frech & Miller, 1999) found that Medicaid formulary restriction in the state of New Hampshire resulted in a 14-45% reduction in the use of all psychotropic medications for schizophrenia. However, this also resulted in a rise in outpatient visits to community mental health clinics, emergency rooms, and partial

hospitalization programs. When formulary restrictions were subsequently discontinued, medication use and health care visits stabilized to previous levels.

In the opinion of mental health advocates, fail-first policies are thought to be dangerous and produce unnecessary suffering for people with schizophrenia (Duckworth & Fitzpatrick, 2008). These insurance related policies require people to initially try less expensive, usually older, possibly less effective antipsychotic medications. Individuals are only able to take a more expensive drug if they fail the preliminary attempts. This is not only frustrating and risky for individuals and families, but it has not been cost-effective (Duckworth & Fitzpatrick). This policy also compromises the treatment options presented by psychiatrists, and does not support the choices of the consumer with mental illness. The National Alliance on Mental Illness (NAMI) opposes all fail-first policies, and is active in lobbying efforts with Medicaid surrounding this issue ([www.nami.org](http://www.nami.org)).

In addition to detrimental societal stigma surrounding mental illness, individuals and families can be constrained by policies and attitudes within the mental health bureaucracy. This is inclusive of fiscal disincentives for public sector programs as well as concern for legal or malpractice risk within the mental health community. For example, individuals who are known to be non-adherent to medication regimens have more difficulty finding appropriate, safe residential care (Blackwell, 1997). Residential programs, such as group homes, often turn away clients who have a significant history of non-adherence due to safety concerns over possibilities for violence. Additionally, since group homes are businesses dependent on funds to operate, it is riskier to admit individuals with medication adherence problems because they are more likely to leave behind empty beds if they are hospitalized for relapse (Blackwell).

Continuity of care, an important issue in supporting medication adherence, is also affected when individuals do not follow prescribed pharmacological treatment regimens (Blackwell, 1997). For example, outpatient psychiatrists have the right to “close the chart” on individuals who are non-adherent to medications. Individuals with schizophrenia have an increased risk for relapse, with the potential to have particularly awful symptoms after withdrawal from their medications in comparison to the typical relapse (Blackwell). Consequently, psychiatrists are at increased risk for malpractice if the client is part of their caseload. When this occurs, the lack of continuity in care of the individual with schizophrenia, particularly those who reject medication, does not serve the person well. This unfortunate community system may lead to mistrust instead of healthy therapeutic alliances (Blackwell).

Access to medications by people with schizophrenia, including picking up prescriptions and re-fills, is also an issue that can act as a barrier to medication adherence. For example, negotiating a bus system, even when this option is available, can be a challenging and frightening experience when one is suffering from symptoms such as disorganized thinking, auditory hallucinations, and paranoid delusions. Using the bus, of course, assumes that the client can afford to pay for this service (Blackwell, 1997). Also, the client who is not able to drive due to symptoms, license repossession, or lack of a vehicle is dependent on others to order re-fills, collect, and manage financial transactions.

Another important piece of legislation that is supported in a majority of the United States (Swartz et al., 1999) is that of involuntary outpatient commitment. The main goal of this policy is to facilitate adherence to treatment in the community,

including participation in outpatient mental health programs, consistent monitoring of medication adherence for people with mental illness, and restrictions on drug and alcohol use (Durham & La Fond, 1996; Swanson, Swartz, Elbogen, Wagner, & Burns, 2003). This is achieved through a court mandate by a judge, after a petition has been put forth by citizens, a peace officer, or physician on behalf of the mentally ill person who is dangerous to himself or others or is unable to provide for basic personal needs (McFarland, Faulkner, Bloom, Hallaux, & Bray, 1990).

Although some support exists for the policy, involuntary outpatient commitment remains controversial. Those who are against outpatient commitment believe that this type of law implies that patients cannot think for themselves, which further contributes to the stigma of mental illness (Allen & Smith; Hoge & Grottole, 2000). Also, the fragmentation of community mental health services have been cited as an area of concern over the ability to accurately and efficiently follow through with court mandates (Appelbaum, 2001).

Certainly, other community barriers such as mental health parity, health care policies, and influences of the media (Appelbaum, 2001) also impact the ability of clients to carry out the occupation of medication adherence. However, this section has provided a flavor of the socioeconomic and policy impacts that are very much part of consumers' daily living environments.

### **Occupation and Recovery**

Occupation concepts blended between PEO and recovery include the created meanings of medications, as well as the connection between recovery and everyday

activities (Borg & Davidson, 2008; Christiansen, 1999; Deegan, 1996; Deegan, 2005; Fidler & Fidler, 1978; Karp, 2006; Peloquin, 2006; Peloquin, 2002; Pettie & Triolo, 1999).

Within the PEO Model, occupation is defined as self-directed tasks or activities that a person engages in for the purpose of meeting intrinsic needs for self-maintenance, expression, and fulfillment within the context of personal roles and various environments (Law et al., 1996). The recovery model, without using the term occupation, emphasizes notions of self-agency, hope, and respect as people with illnesses engage in their lives (Deegan, 1996; Deegan, 2005; Noh, Choe, & Yang, 2008). Furthermore, recovery is proposed by Borg and Davidson (2008) to be defined within the context of everyday activities.

Occupational therapy, as a profession, values *doing* aspects of occupation, understanding that participation in meaningful life occupations is essential to well-being (Christiansen, 1999; Reilly, 1961; Peloquin, 2002). As Christiansen eloquently states, “one of the most compelling needs that every human being has is to be able to express his or her unique identity in a manner that gives meaning to life” (p. 548). Occupations serve as ways to express personal identity, which in turn bestows life meaning. Christiansen proposes identity to include both self and social components, including the view individuals have of themselves and the views held by society.

Although antipsychotic medication is the first line of treatment for positive symptoms of schizophrenia, one must also consider the occupations of daily life in which people with schizophrenia engage. It can be assumed that a significant reason one may

take medications that effectively improve symptoms is to allow engagement in the occupations of life that contribute to one's identity.

The idea of adhering to a prescribed medication regimen as occupation could be imagined in one of two ways: 1) medication could be meaningful or not meaningful in and of itself, or 2) medication could be a "means to an end" allowing or constraining a person's engagement in other significant occupations of their choice. So, what do individuals find meaningful on a routine basis? In essence, what awaits the person with schizophrenia after the pill is swallowed?

The illness of schizophrenia, in addition to possible side effects of antipsychotic medication, can contribute to disengagement in occupations (Bejerholm & Eklund, 2006). The level of engagement in occupations by individuals with schizophrenia varies along a continuum (Bejerholm & Eklund, 2006; Bejerholm & Eklund, 2007). Engagement varies from being isolated and performing quiet activities with little meaning to the opposite spectrum of being largely engaged in meaningful and even social activities (Bejerholm & Eklund, 2006).

In this particular study, participants with schizophrenia who were categorized as mainly disengaged in terms of occupational participation tended to focus on living tasks that represented a form of survival throughout the day such as eating, sleeping, or smoking (Bejerholm & Eklund, 2006). They also relied quite extensively on social supports, such as family members who cooked them meals. Individuals who were disengaged throughout some of the day performed tasks for short periods of time, referred to as activity peaks, and even socialized to some degree, but spent long hours

engaged in passive activities that held little meaning for them (Bejerholm & Eklund, 2006).

Conversely, when participants were considered to be largely engaged during the day, they maintained a continuous flow of a variety of occupations that provided a sense of meaning and involved a fair amount of social interaction (Bejerholm & Eklund, 2006). In a later study by Bejerholm & Eklund (2007), participants indicated that higher levels of participation in occupations were related to higher self-related variables, fewer symptoms, and better quality of life. The converse was also true in that lower levels of participation were related to lower self-related variables, more symptoms, and poorer quality of life (Bejerholm & Eklund, 2007).

It can be postulated that medication management, encompassing each aspect of the act of taking medications, can be a self-care occupation that theoretically enables people to engage in other occupations of life that are meaningful, as the previous examples illustrate. Indeed, the recovery model supports the role of everyday, ordinary activities in the process of the search for wellness (Borg & Davidson, 2008; Davidson et al., 2009; Jenkins & Carpenter-Song, 2005).

The connection between recovery and everyday activities is an example of viewing medication as a pathway to participate in what is regarded as personally meaningful (Borg & Davidson, 2008). Individuals in recovery have revealed the unfolding process of participating in regular activities of daily life, such as interacting with other people in ordinary environments, shopping, taking children to the bus stop, or walking the dog. They have also highlighted the importance of “just doing it,” signifying

the trial and error process of living with their illness, including side effects and worries surrounding medications (Borg & Davidson, p. 134).

But do medications have meanings in and of themselves? Based on these ideas surrounding engagement in occupation, can we say that medication adherence is an occupation? Taking medications can certainly be seen as an activity that is intimately tied to health management. However, outside of a connection with health, it would be a stretch to describe taking medications as intrinsically motivating. It could be theorized that few people would actively seek out the opportunity to take medications, and most would not likely choose medications if it were deemed unnecessary.

The meaning and symbolism attached to taking medications, particularly psychotropic medications, could perpetuate individuals' view of themselves as that of someone who is sick (Karp, 2006; Seale et al., 2005). The concept of medications as a symbol, however, needs further definition. It will be interesting to note whether participants in this study allude to symbolic concepts of psychiatric medications and furthermore, how meanings attributed to medications may link with other life occupations.

### **Multiple Case Study Methodology**

*“Achieving the greatest understanding of the critical phenomena depends on choosing the case well”* (Stake, 2005, p. 450).

Roe et al. (2009) have suggested that the future direction of medication adherence studies should tend toward awareness of profoundly subjective experiences such as feelings and attitudes, which are not currently well-understood. Because medication

adherence is not a simple problem and stems from a variety of influences that are inherent in non-linear human behaviors, purely quantitative methodology is unlikely to reveal layers of depth (Gray, Robson, & Bressington, 2002; Kikkert et al., 2006; Roe & Swarbrick, 2007; McCann, Clark, & Lu, 2008; Zygmunt et al., 2002).

Case study is the principal approach to this research, defined as a formal method of examining a variety of social science related issues (Yin, 2009). In particular, case study methodology is fitting for “how” or “why” questions related to complex, non-linear issues such as human behavior (Yin, p.10). Although this method has strengths and limitations, as would any other, case study designs allow researchers to investigate phenomena through varied sources of evidence. In fact, incorporating a variety of sources to generate data about a case serves to improve the potential for quality evidence (Yin).

Including a number of participant cases, as in the multiple case method used for this research, is more robust in comparison with single case studies (Yin, 2009). In general, Yin suggests that choosing a number beyond a single case will contribute to the strength of the evidence. The rationale for its robustness lies in its inherent ability to capture rich data from multiple participants in which comparisons can be made within and across cases (Yin).

The decision of choosing a particular number of cases lies with the researcher. A rationale for choosing a small number of participants includes the ability of the researcher to describe the multi-dimensional, potentially interrelated features of adherence, social support, and recovery as they emerge in the contexts of life with chronic illness.

Choosing more participants may limit a researcher in the ability to provide rich, contextual descriptions. On the other hand, choosing too few cases does not permit comparison of patterns and variations.

Case study research can be limited to purely quantitative, qualitative, or a combination of these methods (Yin, 2009). In fact, mixing methods can be a means to reduce biases that single methods may possess, and may serve the purpose of informing the other method (Creswell, 2003). Specifically, methods may be integrated so that quantitative research supports qualitative research, or vice versa (Yin).

When designing a case study, it is particularly meaningful to choose viable and unique cases to research the problem (Yin, 2009). To do so has extensive implications as to who the participants will be and where they will be recruited, in addition to the findings. Choosing cases wisely, who meet criteria and pose the best learning potential, will better ensure the ability of the researcher to answer research questions posed at the outset of the study (Yin).

### **Qualitative Methods**

Qualitative research seeks active participation of participants using a variety of methods such as observation, interviews, e-mails, pictures, or other documents (Creswell, 2003). In addition, a variety of methods can be utilized to gain understanding of viewpoints and theories including narrative, phenomenology, ethnography, grounded theory (Creswell; Denzin & Lincoln, 2005).

One of the primary characteristics of qualitative research within the array of research design choices is the emergent versus predicted nature of variables (Creswell,

2003). In other words, dimensions become apparent in the data provided by participants rather than isolating factors at the onset of the study. This can be further emphasized in the tendency of qualitative research to assume a *constructivist* viewpoint (Creswell). That is, traditional claims of knowledge have assumed certain assumptions at the onset of research, whereas the constructivist viewpoint respects subjective views of individuals as they create meanings of their own real life experiences (Creswell).

It is through qualitative research inquiry that perspectives of individuals from diverse backgrounds can be investigated (Denzin & Lincoln, 2005). This approach is most suitable to recognize the individuality of each person's recovery process and relationships with medications, and to evade premature judgments about which dimensions of adherence are prominent. More importantly, the qualitative approach can potentially be used to inform beyond the level of identification, shedding light on *how* dimensions may interact with one another according to valuable perspectives of individuals (Creswell, 2003).

### **Summary**

This chapter provided a comprehensive overview of literature related to topics that have both direct and potential implications for this study. The review encompassed subjects of schizophrenia related disorders, medication adherence for individuals with schizophrenia, families of individuals with schizophrenia, PEO model, recovery model, integration of PEO and recovery models, and case study methodology in conceptualizing the problem of medication adherence. The next chapter will review methodology for the study of medication adherence, social support, and recovery by means of perspectives of individuals with schizophrenia and their families.

## CHAPTER 3: METHODOLOGY

### **Purpose of the Study**

The purpose of this study was to describe experiences with psychiatric medication adherence from the perspectives of four consumers with schizophrenia spectrum disorders and four key family members who serve as social supports. In addition, this study sought to explore how medication experiences could be embedded within the context of personal and familial viewpoints of mental health recovery. Transcribed interviews and recovery questionnaires from multiple case studies were subjected to descriptive analysis within and across multiple cases.

### **Research Questions**

Through the perspectives of recovery (Anthony, 1993; Davidson et al., 2009) and Person-Environment-Occupation (PEO) [Law, 1996] models, the following research questions were considered for the consumer with schizophrenia: a) how do consumers with schizophrenia experience medication adherence; b) how do consumers experience social support by families surrounding medication adherence; and c) do consumers view medication adherence as part of their recovery processes; and if so, how?

In addition, the following research questions were considered for the key family member of the consumer: a) how do family members view experiences with medication adherence; b) how do family members define their social support role relative to consumers' medication adherence; and c) do family members view medication adherence as part of consumers' recovery processes; and if so, how?

## Research Design

A multiple case study research design (Yin, 2009) was used to explore individuals' and key family members' experiences with psychiatric medication adherence within the mental health recovery processes. The primary case was defined as the consumer with mental illness who has had experiences with psychiatric medication adherence. Family members were a secondary source of data triangulation, serving to inform the perspectives of consumers.

Both qualitative interviews and quantitative questionnaires were used in data collection. However, the dominant method (Creswell, 2003) in this dissertation study was qualitative, since the main focus was to describe experiences with medications and to identify how this may be embedded within the context of viewpoints of mental health recovery. Quantitative recovery questionnaires functioned as an adjunct triangulation source for explication of core ideas about mental health recovery. Therefore, the quantitative method was intended as a support for purposes of elaboration and development (Creswell).

Qualitative and quantitative data were collected concurrently in one phase of the study (Creswell, 2003). This nested arrangement has been conceptualized by Yin (2009) as a survey within multiple case studies. Both methods yielded data that were analyzed with the intention of describing perspectives of consumers with mental illness and their family members. The goal was to unearth the essence of participant experiences with medications to glean information that might be useful in the management of schizophrenia spectrum disorders.

Theoretical models of PEO (Law, 1996) and recovery (Anthony, 1993; Davidson et al., 2009) provided a lens from which to examine subjective experiences. In addition, the Expanded Family Life Cycle model (Carter & McGoldrick, 2005) aided in the interpretation of individual and family developmental tasks that occur in the context of chronic illness (Jungbauer et al., 2004; Rolland, 2005). This model provided a necessary context for developmental tasks of the individual in early adulthood, as well as the family system that is integrated with, and affected by, the member with chronic mental illness.

### **Rationale**

*“Why don’t you ever ask me what I do to help myself?”* (Strauss, 2008, p. 201)

The subjective experience of medication adherence for individuals with schizophrenia should not be ignored, but as the quote illustrates, it often is. Reasons for the lack of focus on subjective experiences are numerous, but as Strauss (2008) contemplates, it could partly stem from the desires of those working in mental health to be considered “serious” scientists, equal to other science professions. He also postulates that subjective experiences are more difficult to analyze, at least according to traditional scientific principles. Strauss supports the use of subjective experiences in clinical and research realms, explaining that individuals with mental illness could be negatively affected by the lack of opportunity to relate their personal experiences.

Moreover, research that focuses on subjective experiences is pertinent to exploring areas where “little is known and hypotheses are difficult to generate” (Carpentier, 2006, p. 35). In this study, a major purpose was to explore dimensions of medication experiences, family as social support, and ideas toward recovery with the goal

of gaining rich, deep understanding of the layers that encompass adherence. The multiple case study approach offers an opportunity for more sophisticated analysis in the comparison among participants when compared with the single case method (Yin, 2009).

Currently, the mental health field does not appear to have the language to discuss these issues as interrelated constructs as few studies have explored the problem in this fashion. The ways in which these multiple dimensions may be interrelated was left to participants to reveal. Moreover, because the constructs analyzed in this study were intricate and prone to a variety of influences, it was important to assess what predominant influences may account for adherence in each unique life circumstance. Resultant patterns and variations across cases allowed the researcher a deeper understanding of the phenomena being studied (Yin, 2009).

As discussed previously, quantitative studies on the topic of medication adherence are vast, but many have not been capable of revealing the intensity of human experiences. Although past studies on adherence have certainly been informative in a number of other ways, research that emphasizes objective data has ultimately reduced the ability to capture complex, underlying processes related to adherence behaviors.

In addition, choosing to reduce the complex phenomenon of medication adherence by attending to select variables, as might occur in quantitative research, may result in limitations or biases if they alone were chosen for this study (Creswell, 2003). Therefore, multiple case study research is beneficial to explore complex dimensions and relationships surrounding medication adherence, including the potential influences of social support systems and views of mental health recovery.

The impetus for research has undoubtedly followed the realization of mental illness as a biological disease, and the primary focus on medications as a key intervention. However, it is perhaps a newer revelation that researchers may need to return to the drawing board; that is; to listen carefully to the perspectives of individuals that live with illness, as well as those who support them. After all, despite the advent of newer antipsychotic medications with fewer side effects and multiple attempts to improve adherence, rates have not changed for at least four decades (Kikkert et al., 2006; Velligan et al., 2009).

### **Strengths and Limitations of Design**

An advantage to case study research includes its capability for assimilating an assortment of facts from different sources (Stake, 2005; Yin, 2009). For example, triangulating data could include interviews, newspapers, telephone conversations, and field notes to name a few (Yin). The process of gathering case study data occurs over the entire period of the study (Stake). Also, attention to various influences and contexts are considered in the course of designing and carrying out case studies (Stake; Yin). Case study research is an appropriate choice for studying complex, problematic processes involved within individual lives (Creswell, 2003; Stake). It is especially fitting to study real-life experiences, when the limits of how these phenomena interact with context are not apparent (Yin).

Multiple case studies have several advantages over single case study designs (Yin, 2009). One primary advantage of multiple case studies is the fact that they are well-respected in terms of the capacity to provide convincing evidence. Also, researchers can

potentially choose participants for each case carefully so that, in essence, replication is accomplished with each case (Yin). Replication in multiple case studies refers to the concept of duplicating a finding so that an original finding is more “robust” (Yin, p. 54). Replication is considered a distinct advantage to multiple case studies versus single case studies. In this way, it differs from the parallels that are often drawn, for example, between multiple respondents in a survey (Yin). Although medication adherence could certainly be studied using a single critical case, or a rare case, it is more apt for this particular study to compare similarities and differences in several consumers’ and families’ lives.

Some may argue that case study research lacks rigor and introduces subjective bias (Yin, 2009). This is all the more reason to design a systematic, well planned study where research questions are concise and every effort is made to reduce bias and improve validity (Yin). Case studies should be approached carefully and methodically as with other research designs, but this is not a procedure that is undemanding. In fact, it is the development of a sound research design that may constitute the most difficult part of carrying out case study research (Yin). It is important for the researcher to consider the limitations and make decisions about how to improve the rigor of the design.

Another widespread concern is that one cannot generalize from case study methodology (Yin, 2009). However, important to recall is that many quantitative studies have been done regarding aspects of medication adherence, but little replication and perhaps narrower focus on theorized variables has led to a similar inability to generalize findings. In this case study, influences will not be hypothesized or presumed in advance, but will be permitted to emerge in potentially novel patterns.

Furthermore, Creswell (2003) suggests that using both qualitative and quantitative methods involves researcher expertise in order to effectively gather data and integrate the analyses of both types of data. Since qualitative and quantitative data differ in form, proficiency by researchers to analyze data and resolve divergent issues is essential. In addition, when both methods are asymmetrical in terms of priority, this can add to potential dilemmas of interpretation (Creswell). However, potential dilemmas are reduced in this study since qualitative data will be the primary method used, with quantitative data present only for the purpose of triangulation to explicate about popular recovery viewpoints. To conclude this section, it is also apt to reveal an increasingly palpable opinion that adding quantitative to qualitative data may detract from the richness of subjective data. In essence, some researchers have voiced concerns that subjective experiences are being watered down by objective findings (Denzin & Lincoln, 2005).

### **Participants**

In this study, cases were chosen for the purpose of contributing to the robustness of the research (Yin, 2009). Also, selected cases permitted the researcher to describe in-depth issues related to medication adherence, social support, and recovery for consumers and families. The case was defined as the consumer, with their family member serving to inform the primary case.

Seven consumers expressed interest in the study during the recruitment phase of the research. Each consumer was screened on the telephone to determine whether they met criteria. Two consumers did not meet criteria because of diagnosis and/or were not living in the community. One additional consumer who was found to meet criteria

decided not to participate after the telephone screening. The researcher reinforced that non-selection for the research study was by no fault of their own, and they were thanked for their interest. Four consumers and four family members were selected for this study. No one dropped out of the study once data collection began.

### **Criteria**

Inclusion criteria (*Figure 2*) for this study included young adult males and females with a diagnosis of schizophrenia or schizoaffective disorder between the ages of 22 and 35 years old. In addition, consumers were required to have been mentally ill for at least 2 years, living in the community, and be willing to discuss their experiences with psychiatric medication adherence. Exclusion criteria included unwillingness to discuss medication experiences, living with mental illness for less than 2 years, not living in the community, role reversal of consumer-parent relationship, or not meeting criteria for age, diagnosis, or disagreement to consent to research.

### Inclusion Criteria

- Diagnosis of schizophrenia spectrum disorder per self/family report
- Current age of 22-35 years
- Living in the community
- Diagnosed with mental illness for at least 2 years per self/family report
- Be willing to discuss experiences with psychiatric medication adherence
- Identification and consent of key family member (i.e. parent, sibling, grandparent, aunt/uncle, cousin, spouse) who has contact with consumer at least twice per week
- Informed consent of consumer and family member to participate in the study

### Exclusion Criteria

- Not willing to discuss experiences with psychiatric medication adherence
- Lived with mental illness less than 2 years
- Not living in the community (hospitalized)
- Consumer is parent of family member (role reversal)
- Not meet criteria for diagnosis, age, and/or consent

Figure 2: Inclusion and Exclusion Criteria

Consumers who were chosen for the study suggested one family member who has contact with them at least twice per week, who subsequently agreed to participate in the study for private interviews and surveys. Family members for this study were not limited to a designated relationship type but may have included parents, siblings, spouses, or other extended family members who have contact with the consumer. The family members whom consumers independently chose for this study were all parents; two mothers and two fathers.

### Recruitment Procedures

Study participants, including four pairs of consumers and families, were recruited in the community through grassroots organizations such as the National Alliance on Mental Illness (NAMI), community mental health programs, previous clinical

relationships, or other non-profit community contacts. Recruitment began with consumers first, followed by selection of one key family member whom they agreed to be a part of the study.

For the purpose of orienting the reader to NAMI, this is a community organization that began in the late 1970's by families of persons with mental illness. Now widely utilized by consumers and families alike, NAMI provides education, advocacy, support, and research ([www.nami.org](http://www.nami.org)). For example, some popular offerings via NAMI include support groups and family education courses. Due to the nature of community mental health sources such as NAMI, it can be theorized that families and consumers are distinguishable in terms of reaching out for support, using resources in a fairly organized fashion, and perhaps being exposed and rooted as an advocate for mental health needs. As such, this population of participants may be unique in comparison to other individuals and families who do not access such support systems.

As mentioned, community resources were utilized through personal connections and volunteer professional associations in the researcher's geographic location. Fortunately, an invitation was extended to present the study to members of the Department of Mental Health and Substance Abuse in Loudoun County, Virginia. Members of this organization approved the researcher's request to post flyers within mental health outpatient and day programs. In addition, the researcher developed a business card with contact information about the study, which were distributed with flyers or handed out to various mental health community contacts as appropriate.

Also, contacts were shared in the community that resulted in meeting leaders of NAMI organizations and drop-in centers. One such contact was a NAMI executive who agreed to post information about the study in a newsletter and offered to introduce the study during telephone business calls with constituents. Another NAMI executive invited the researcher to attend a large meeting where a microphone announcement was given about the study. And yet another lucrative contact was a consumer who was in charge of a community drop-in center. She eagerly invited a presentation to a number of consumers who attended the center.

Interestingly, an overall impression during recruitment was that numerous families were attracted to participation in the study. This was particularly true during NAMI meetings, for example, when the researcher was able to make a microphone announcement and mingle with attendees afterwards. However, more than one family explained that their adult children with schizophrenia would be hesitant to share their feelings about medications. Therefore, they could not participate, but were disappointed that they could not share their family experiences. Also, notably, some consumers with bipolar disorder or other severe mood disorders phoned to inquire about the study, and wished that they could impart their experiences.

The area in which participants were recruited included neighboring counties of the Virginia, Maryland, Pennsylvania, and Washington, D.C. corridor. All forms of recruitment such as flyers (Appendix B) and e-mail scripts (Appendix C) were approved by the IRB.

## Screening Procedures

Participants may have indicated interest in the study in a number of ways. For example, a consumer or family member may have seen a flyer about the study and consequently contact the researcher via e-mail or telephone. Or, as mentioned previously, participants may have expressed interest in person, for instance during a visit to a community group, and ask that the researcher initiate contact. These are just two examples of a variety of possible scenarios.

For this study, interested consumers and families were screened on the telephone in order to determine eligibility. To guide the initial telephone meeting, a telephone screening protocol (Appendix D) was utilized for both consumers and family members. This screening protocol was beneficial to ensure that vital points of information regarding the research were shared with potential participants, in addition to asking questions that relate to approved criteria. As eligibility was established, the initial telephone conversation also provided the opportunity for a brief informal consent to meet in person.

For this study, the telephone screening was initiated by the consumer in three cases, and by the therapist in one case according to consumer preference. During the first in-person meeting, participants had the opportunity to clarify questions about the study and complete written consents (Appendices E and F). During telephone screening of the consumer, and his or her indicated interest to proceed with the study, the consumer identified a family member whom they would feel comfortable asking to participate. Permission was obtained by the consumer to contact the identified family member.

## Characteristics of Sample

A sample of convenience was chosen for this study (Tashakkori & Teddlie, 1998) with the goal of achieving developmental homogeneity by selecting individuals in the early adulthood phase of life, including males or females aged 22-35 years. The young adult consumer sample was given highest priority for this study in terms of selecting cases that are instrumental to understanding medication adherence.

Cases were selected based on satisfaction of inclusion criteria and according to who may pose the best potential for optimal learning (Stake, 2005; Yin, 2009). Four consumers, two males and two females, in their early to mid-thirties were selected for this study (*Table 1*). Four parents of the adult consumers, two mothers and two fathers, in their late fifties to late sixties participated in the study (*Table 2*). The names of each consumer and family member have been changed to protect their identity.

Dan, the first consumer participant, is a 33 year-old Caucasian male with schizoaffective disorder. He initiated a call to the researcher in March 2011, preferring to remain anonymous. His intention was to find out more about the study without having to reveal his name. He had heard about the study via a NAMI e-mail communication. Once he acquired the information he needed, he stated that he would be willing to give his name and participate in the telephone screening. When it was determined that he met criteria, he identified his mother, Sheila, as the family participant he wanted to participate. It is apt to note that Sheila had the impression that Dan was diagnosed with schizophrenia, and not schizoaffective disorder.

Dan signed the written consent during the first in-person meeting, which took place partly in a library conference room and in the researcher's vehicle. The first interview was approximately one hour and twenty minutes in length. The second meeting took place in Dan's basement apartment because he had difficulty with scheduling use of the car he shares with his mother. The second interview was one hour and a half. He also completed his recovery surveys at the end of the second interview. The third meeting for the purpose of validation was also face to face in Dan's basement apartment, which was one half hour in length. Each interview was audio-taped. Of note, it was later decided that the third meeting for subsequent consumers need not be in person nor audio-taped, and the method was modified to be telephone-based. This decision was made for purposes of decreasing the intense amount of time required of consumers, and because the validation check did not seem to require audio-taping.

Sheila (68), Dan's mother, signed the written consent during the first and only face to face meeting in March 2011, which took place outdoors in a semi-private shopping area next to an exterior water fountain. The interview and survey were completed in the same day, with one break during the interview for Sheila to go pick up Dan from work. When the weather became cooler, the second part of the interview resumed inside of a semi-private hotel lobby. The interview lasted for one and three quarter's hours. The telephone interview for the purpose of validation was completed in August 2011.

Table 1

## Consumer Demographics

<b>Participant Code</b>	<b>Age/Gender/Race Marital Status Income</b>	<b>Diagnosis/# years with mental illness</b>	<b>Living Situation</b>	<b>Education/Work Status</b>
<b>DS01C “Dan”</b>	<b>33 y/o Male/Caucasian Single ; Under \$25K</b>	<b>Schizoaffective disorder/ ~15 years</b>	<b>Rents basement apartment outside of mother’s home</b>	<b>BS degree/ works part-time at grocery store</b>
<b>DS02C “Rebecca”</b>	<b>35 y/o Female/African- American Single; Under \$25K</b>	<b>Schizophrenia/ ~5 years (Depression &amp; ADD before schizophrenia)</b>	<b>Lives in parents home at time of interview/ moved to condo at follow-up</b>	<b>BS degree/ volunteers part- time</b>
<b>DS03C “Sean”</b>	<b>35 y/o Male/African- American Single; Under 25K</b>	<b>Schizophrenia/~15 years</b>	<b>Lives in own apartment</b>	<b>High School/ studying for test to work in union</b>
<b>DS04C “Alison”</b>	<b>34 y/o Female/Caucasian Married; 31K-60K</b>	<b>Schizoaffective disorder/~15 years</b>	<b>Lives with husband in apartment</b>	<b>BA degree/ works full-time at public library</b>

Rebecca, the second consumer participant in this study, is a 35 year-old African-American female with schizophrenia who was recruited on the basis of a previous clinical relationship. The patient-therapist relationship ended approximately 6 months prior when Rebecca was discharged from the research hospital in which the researcher is employed. She was informed about the study during a telephone conversation with the researcher, and was asked to call the researcher back after thinking it over.

Because of the pre-existing clinical relationship with Rebecca, the researcher made certain to immediately emphasize that the study was completely voluntary, and that

no one would be upset with her should she decide this study was not a good fit for her. It was explained that participation or non-participation in the study would in no way impact her ability to utilize the researcher's workplace for future health care research which were not associated with this dissertation study.

Rebecca called back on her own will approximately three days later, and reported that she would like to participate in the study. A telephone screening was completed, where Rebecca identified her mother, Maureen, as a family member who could participate in the study. Maureen was also known to the researcher from the previous clinical relationship with her daughter in a voluntary research hospital setting. Permission was gained from Maureen and initial meetings were scheduled for April 2011.

Rebecca preferred to meet in her empty condominium (bar two chairs), where she had vacated due to financial and health reasons, but hoped to be able to move back in after repairs had been made. She had recently been awarded disability benefits, and there was a chance that she could now afford to live there. For the meantime, she resided at her parents' home. Because Rebecca desired complete privacy, she did not want to be in her parents' home during the first interview. She did not have a car or a ride to her condominium, and public transportation tended to increase her paranoid feelings. She requested a ride to her home via the researcher.

Written consent was completed before the first interview. Rebecca asked for one longer interview, but it turned out that she became ill with a headache part way through the first meeting. The first interview lasted for one hour and five minutes. Therefore, a

second interview occurred at her parents' home, which she agreed to do since her parents were working and would not be in the home. This interview lasted for thirty-six minutes. The telephone interview was accomplished via telephone in August 2011.

Maureen (59), Rebecca's mother, asked that the researcher meet her in a private conference room at her workplace on a weekend. Aside from a few minor work interruptions, she was able devote her attention to the interview process. Both Maureen and the researcher were at ease in talking with one another, especially because therapeutic rapport was developed previously. She completed the written consent before the meeting and completed her interview and survey in two parts on the same day (April 2011). The main interview was one hour and fifty-three minutes in length. The phone interview was finalized in September 2011.

The third consumer participant, Sean, is a 35 year-old black male with schizophrenia. He became curious about the study when he noticed a flyer in a consumer-run mental health drop-in center. He phoned the researcher and left her a voice mail to communicate interest in the study. The researcher returned Sean's call and a telephone screening was completed. He identified his father, Paul, as a family member who could engage in the study.

Coincidentally, the researcher had been invited to provide a brief talk about the study at this very location the next day, and Sean planned to be present. Following the presentation, he continued to communicate interest and the main meeting was scheduled to be done in May 2011 at the drop-in center in a private conference room. Sean preferred to have one longer interview rather than two shorter sessions, which was

accomplished given his tolerance for questioning. This main interview was approximately one and three quarter's hours. His follow-up phone interview was completed in October 2011.

Sean's father, Paul (58) decided to meet at the drop-in center for his interview on a separate day in May 2011. Paul arrived using a cane for mobility, and slightly out of breath. He was a cheerful man who was laid back and glad to share his experiences. His interview and survey successfully concluded in the same day. The interview lasted for approximately one and three quarter's hours. A follow-up telephone interview was completed in October 2011.

Alison was the fourth and final consumer participant in this study. She is a 35 year-old Caucasian woman with schizoaffective disorder. She, along with her friendly new husband and charming puppy, were in attendance at the presentation at the drop-in center. She was inquisitive about the research and it did not appear difficult for her to ask clarification questions. She approached the researcher after the talk was finished, expressing interest in the study. She stated that she was surprised "anyone would be interested in this" but was pleased that someone wanted to ask about medications. She exchanged contact information with researcher and stated that her preference was to be contacted in order to schedule the interview.

Once screening was complete and she was found to meet criteria, a meeting was scheduled for June 2011. Like the third consumer participant, Alison preferred to have one main interview instead of two separate sessions which was feasible given her emotional endurance, apparent in her ability to maintain full-time employment. She

identified her father, Richard, as a family participant who could participate in the study. She revealed that she would rather not have her spouse in the study, since she was newly married and she felt he would be unfamiliar with her history of illness and medications. She casually mentioned that her father was ill with schizophrenia, and that he was an attorney before his retirement. She knew her father would be closest to the details of her life with illness. On first thought, her story from the perspective of her mentally ill father would be compelling.

Finding a space for Alison's interview proved to be challenging, as she expressed hesitation about meeting at the drop-in center. She explained that she barely attended the center, and did not know "all those people." Since she worked at the library, she suggested meeting at a library conference room. However, after a few phone calls to various local libraries, it was apparent that conference rooms were difficult to come by for two person meetings. The minimum number of people for these rooms was usually at least three.

Looking at the options available and considering confidentiality, she agreed to meet at the drop-in center. This worked out fine, aside from Alison's occasional shifts of attention to muffled conversations outside of the conference room door. Alison signed the written consent form at her meeting. Her interview and surveys were accomplished that day. The interview was one and three quarter's hours in length. The follow-up telephone call was finished in October 2011.

Richard (66) was contacted for the telephone screening and to schedule his main interview. He was comfortable on the phone it seemed, but he was suspicious of

government involvement with the research study. When it was explained that this was an independent study in fulfillment of a university degree program, Richard relaxed. He was talkative and took pleasure in discussing his interests. The interview was scheduled to happen at the drop-in center, back to back with Alison's interview. Since he did not have a driver's license, Alison provided transportation to the meeting. Richard completed his interview and survey that day. The interview was one and a half hours in length. Since Alison had left the drop in center by the end of the interview, Richard requested a ride back to his home. The final telephone interview was fulfilled several months later in October 2011.

Table 2

## Family Demographics

<b>Participant Code</b>	<b>Age/Race Marital status</b>	<b>Education</b>	<b>Household Income</b>	<b>Frequency of contact with consumer</b>
<b>DS01F "Sheila" Dan's mother</b>	<b>68 y/o Caucasian Divorced x1 Re-married</b>	<b>MS degree</b>	<b>31K-60K</b>	<b>3-4 times/week</b>
<b>DS02F "Maureen" Rebecca's mother</b>	<b>59 y/o African-American</b>	<b>MS degree Public Relations</b>	<b>&gt;100K</b>	<b>Daily</b>
<b>DS03F "Paul" Sean's father</b>	<b>58 y/o African-American/ Divorced x 1 Separated</b>	<b>MS degree</b>	<b>61K-100K</b>	<b>2 times/week</b>
<b>DS04F "Richard" Alison's father</b>	<b>66 y/o Caucasian/ Widowed</b>	<b>Juris Doctor</b>	<b>31K-60K</b>	<b>2 times/week</b>

## **Ethical Considerations and Review**

This study was submitted for official review and approved by the Towson University Institutional Review Board (11-A029). When a participant indicated interest, the screening procedures were completed via telephone. During the first meeting, consent forms were signed by both consumer and family parties. As the consent forms indicated, participants were free to withdraw from the study at any time without consequence. They also had the option of declining certain questions, or to request early termination of the interview.

Consumers indicated a medical provider as an emergency contact within the informed consent. The researcher and consumer discussed that contact with their medical provider would only be necessary in a case of urgent concern, such as participants' sharing plans for self harm or the harm of others. In non-immediate situations, such as participants' revealing thoughts of stopping medications or skipping medication doses, conversations relative to sharing intent with supports (i.e. family, doctor) would occur as appropriate. However, this was not found to be necessary during any phase of data collection with participants. This researcher was not functioning in a clinical role in this study, and did not undertake significant intervention beyond the use of verbal encouragement and support.

Reimbursement was issued in the form of store or debit gift cards to consumers in the amount of \$40.00. For family members, a store or debit gift card in the amount of \$20.00 was issued. It was decided that the majority of funds would be dispersed to consumers rather than family members, since consumers are the primary focus of the

study. Consumers with severe mental illness also tend toward financial hardship in their adult years. Reimbursement was not advertised in the recruitment or screening process until it is known whether participants met criteria. The rationale for this decision was to reduce the disappointment of consumers and families if they were not selected for the study.

Data are stored on a password protected computer and will be permanently deleted within 3 years or after completion of the research as set forth in regulations by Towson University. In addition, handwritten notes that include telephone screenings and field notes are stored in a locked cabinet and will be destroyed using a cross-cut shredder after 3 years. All data from this study is only accessible to those researchers who have been involved with data collection and analysis.

### **Role of Researcher**

As Yin (2009) states, the skills for case study research are quite vast and detailed. In order to design and carry out a worthwhile and valid case study research project, the investigator should possess skills in a variety of areas (Yin). In addition to the obvious credentialing of the researcher in his or her field of interest, the well-trained researcher should be able to listen well, ask good questions, think flexibly, be aware of preconceived biases, know how to avoid controllable bias, and firmly understand the issue being studied (Yin). The process of research using case study, particularly qualitative methods, requires that the researcher is capable of reflection and is committed to critically contemplate the data (Stake, 2005).

I am the primary designer and interviewer for this dissertation study. My role in this research was the recruitment and selection of participants, interviewing of consumers and family members, and analyzing data. I am a bachelor's trained occupational therapist, with a master's degree in education, focusing on higher education and adult learning. I have 16 years of experience as an occupational therapy clinician, 9 of which have been in the mental health field.

Specifically, I provide part-time clinical services to individuals with schizophrenia in a large biomedical research institution, a backdrop for a strongly focused medical model paradigm. In addition, I have had a small research role as a lead investigator in one previous qualitative study at this institution. I have also completed one case pilot study in the community, which was associated with my doctoral education program. Through engagement in these studies, I have gained beginning practice in designing, collecting, and analyzing mostly qualitative with adjunct quantitative data.

By nature of my clinical training and practice, I am naturally curious about people. Specifically, I am very concerned as to how and why individuals with schizophrenia do not desire to take psychiatric medications. Based on my previous research, and mostly through clinical experiences, my bias is that individuals with thought disorders can articulate their reasoning behind their decisions to alter or stop medications with surprising clarity. Before I began working with individuals with schizophrenia, I may not have believed this.

Over the years, through mentorship from senior colleagues and through experience, I have concentrated quite extensively on guiding individuals in their efforts to

work toward meaningful lives. I have learned that above all, I must work to understand their needs and desires and design occupational therapy programming in such a way that they desire to engage, despite the negative symptoms that may be stealing their drive for life. These qualities of clinical reflection are necessary in successful practice, and are also vital to fruitful case study research (Creswell, 2003; Stake, 2005; Yin, 2009).

In addition, one other well-trained doctoral level associate researcher participated in qualitative data analysis in order to contribute to validity. Specifically, she has a Master's degree in occupational therapy, a Doctoral degree in human development, and 38 years of experience in the field. She is a mental health specialist who is well practiced with qualitative research. Her main role in this study was to learn the coding system envisioned and set forth initially by myself, followed by testing the system as applied to participant data and collaboratively revising the coding system until consensus was reached.

### **Data Collection**

Below, Figure 3 offers a visual representation of the research progression. Beginning with the acceptance of the dissertation proposal by committee members and approval by the Towson University Institutional Review Board (IRB) [Appendix A], the process progressed to recruitment, telephone screening, and signing of informed consents. After consents were completed by consumers and family members, data collection commenced with demographic questionnaires and semi-structured interviews, followed by completion of recovery questionnaires.

After listening to the audio-tapes and writing categorized notes from the interview, the researcher contacted participants to set the final telephone meeting in order to verify that the researcher understood what participants intended to communicate. Following data collection, the researcher began to analyze the data in order to interpret the experiences of consumers and families.

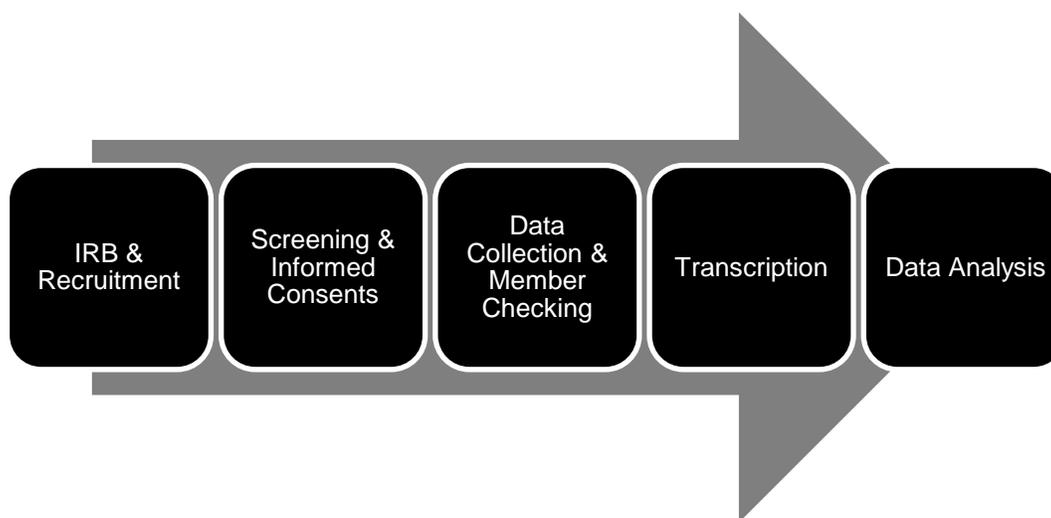


Figure 3: Research Flow

### **Instruments: Qualitative Interviews**

Both the consumer and key family member in each pair were interviewed privately and separately to understand experiences surrounding medication adherence and recovery. All face to face interviews with consumers and families were audio-taped. Handwritten notes were recorded during verification telephone calls. The semi-structured format of in-person interviews provided key questions and possible follow-up questions, but remained flexible to allow for emergence of rich, descriptive narrative as provided through the perspectives of participants (Creswell, 2003).

The interview format for consumers consisted of two separate in-person sessions, or one longer main session if preferred, in which to understand medication experiences, social support, and perspectives of mental health recovery. During the main interview(s), the researcher became acquainted with the consumer and his or her life, followed by asking questions that centered on medication routine and experiences with adherence (Appendix G). Consequently, the researcher delved into in-depth exploration of the person's experiences with adherence, social support with medication, and mental health recovery (Appendix H). The third interview, via telephone, served the purpose of asking follow-up questions and for verification.

Families participated in one face to face interview session. This interview (Appendix I) served the purpose of becoming acquainted with the family member, and to explore the family perspective surrounding medication adherence for their mentally ill relative. In addition, views of the family role as a social support, as well as mental health recovery views were investigated. The second interview, via telephone, allowed the researcher to ask follow-up questions for clarification or elaboration.

For both consumers and family members, the flow of semi-structured interview questions began by becoming acquainted with the participant, progressing toward experiences with medications, and venturing toward gathering participant visions of mental health recovery. It is important to note that questions relative to "recovery" were not introduced until the end of the interview in order to avoid introducing the definition too early in the participants' recollections of their lived experiences with medications.

Since recovery may not be a familiar term for some individuals (Davidson et al., 2009), a simple definition was provided that includes more recognizable terminology. The definition chosen for use in this interview was adapted from original assumptions in the recovery literature by William Anthony (1993), which proposes a collective vision of recovery based on experiences of individuals with severe disabilities. The definition, as it appears below, encompasses the view of recovery as possible by the individual while emphasizing the presence of supportive others as a common feature of recovery (Anthony).

For each consumer and family participant, the following description was read verbatim: *“Some people have defined recovery as the process of moving forward with life with a sense of hope and control over their choices, even though symptoms of mental illness may still be present. Many people also feel that they have been helped toward recovery by others who support them.”* Thereafter, participants were asked to share their thoughts about recovery, including whether or not the above definition applies to their lives.

Again, introducing recovery late in the interview was primarily to gain perspective about their experiences with medications first without introduction of a specific recovery terminology that may or may not be recognized by participants. This allowed participants to freely discuss their lives with illness in terms that are meaningful to them for much of the interview. Introducing recovery terminology generated their perceptions of whether or not their definition of recovery is similar or different from the ways in which it is defined in the literature. The researcher hoped to elicit ways that medications may fit into personal recovery schemas.

**Validity of qualitative data.**

Validity of qualitative data is not achieved in the same way as quantitative data (Creswell, 2003). Because qualitative studies are subjective and not conducive to generalizability, the nuances of validity and reliability are different (Creswell). To improve validity of qualitative research, strategies are incorporated to suggest credibility of results from the positions of researchers, participants, and readers (Creswell).

Strategies for improving validity of qualitative research could include: a) triangulating data sources, b) using follow-up phone call verifications, c) using rich descriptions to help readers share the experience, d) clarifying researcher biases, e) presentation of gaps or discrepant information in data, f) spending a prolonged time in the field to gain in-depth understanding, g) using peer debriefing to provide feedback and suggestions, and h) using an external auditor to review the project (Creswell, 2003).

For this study, one way that validity was improved was by triangulating sources of data which includes the use of different methods of research collection (qualitative and quantitative). Another triangulating source was the interviewing of both consumers and family members who were familiar with one another and could share similar and/or different perspectives about medication adherence and recovery.

Co-analysis with a doctoral level associate researcher in the qualitative coding process also provided a valuable addition to validity of this study. By utilizing an associate researcher, validity increases as viewpoints are discussed between two researchers. Further details relative to sequencing data analysis between both researchers will be discussed at the end of this chapter.

Throughout the dissertation process, a committee provided feedback on the study including review of research questions and instrumentation. Other auditors were utilized by asking fellow occupational therapy colleagues and colleagues outside of the profession to review sections and submit comments or reactions. Also, the completion of a pilot study beforehand in order to test and solve issues related to instrumentation is also a benefit to improving the validity of the main study (Yin, 2009).

Verification was utilized as a method for improving the validity of this study. This was accomplished during the final telephone interviews for consumers and families. When semi-structured interviews were completed, the researcher listened intently to audio-tapes, capturing the participant's experiences without being distracted with line by line typed transcription. Listening to audio-tapes allowed the researcher to, in essence; grasp the holistic picture painted through the participant's expression of ideas. This also served as a method of evaluation for the researcher, verifying that key questions were indeed explored during sessions and gaps in knowledge were identified.

Categorization of ideas brought forth by participants helped to guide the final interview in a way that was clear to participants during the final session. So, the primary focus of the verification phone interview in this study was to reduce errors in a way that is understandable and as unbiased as possible. This strategy served to improve the credibility of this research by asking for valuable participant feedback.

### **Instruments: Quantitative Questionnaires**

The demographic questionnaires for both consumers (Appendix J) and families (Appendix K) were utilized as a means to collect basic background information. Both

consumer and family demographic questionnaires were developed for use in the previous mixed methods pilot study based on thorough review of the literature. Each demographic questionnaire was minimally revised after the pilot study to modify language in order to reflect simplicity and ease.

Specifically, demographic questionnaires were used in order to gather necessary information about age, gender, family relationships, psychiatric symptoms, socioeconomic status, geographic location, support mechanisms, and background relative to the problem of medication adherence. For both consumers and families, demographic information was collected before beginning interviews so the researcher could incorporate background knowledge into interview questions as appropriate.

Consumers were asked to complete two recovery-based questionnaires, the Mental Health Recovery Measure (MHRM) [Young & Bullock, 2003] and the Recovery Attitudes Questionnaire (RAQ-21) [Steffen & Wishnick, 1999]. Families were asked to complete one recovery-based questionnaire, the Recovery Attitudes Questionnaire (RAQ-21) to assess general beliefs toward recovery.

The purpose for using each of these questionnaires was to understand personal recovery views and general beliefs about recovery from the consumer's perspective. Findings from questionnaires informed the narrative data about recovery, allowing the researcher to elaborate. By assessing a number of objective viewpoints about recovery, the researcher could compare viewpoints between consumers and families, in addition to capturing a snapshot of several characteristics that constitute recovery in the literature that may or may not materialize in the lives of participants in this study.

The Mental Health Recovery Measure (MHRM) [Young & Bullock, 2003] is a self-report measure, available in adolescent and adult versions, that includes 30 Likert scale items that assess personal views of recovery (Appendix L). It was originally developed with the input of consumers with mental illness through an Ohio state mental health recovery initiative (Ralph, Kidder, & Phillips, 2000). The original MHRM contained 36 items and was called the Recovery Scale. Psychometric testing of this instrument revealed high internal consistency ( $\alpha = .91$ ). Convergent validity with the Community Living Skills Scale and the Making Decisions Scale was also found (Ralph, Kidder, & Phillips).

In addition to a total score for the MHRM, six subscales can also be deduced that include: a) overcoming stuckness, b) self-empowerment, c) learning and self redefinition, d) basic functioning, e) overall well-being, and f) reaching new potentials. This measure was pilot tested during a previous single case study project by this researcher and found to enhance the generation of concise data regarding personal beliefs about recovery. Again, this instrument can provide a brief picture as to how consumers may view their recovery, in terms of feelings of empowerment, ability to re-build their lives with illness, or capacity to move past challenges to mention a few.

The Recovery Attitudes Questionnaire (RAQ-21) [Steffen & Wishnick, 1999] was developed to measure and compare attitudes about recovery among various groups such as individuals, families, the public, and health care providers (Appendix M). This is the original version of the RAQ and was pilot tested with over 800 consumers, providers, families and students in Ohio. Later, factor analysis revealed that 21 items could be effectively reduced to seven (RAQ-7) with a focus on two underlying themes that

include: a) recovery is possible and needs faith, and b) recovery is difficult and differs among people (Ralph, Kidder, & Phillips, 2000). These two underlying themes accounted for 54% of the variance.

Subsequently, later findings using the RAQ-7 found differences among the groups in their attitudes toward recovery and in the hierarchy of importance for items (Ralph et al., 2000). Therefore, four subscales were designed for use with consumers, families, health care providers, and the public. Each of the four subscales, due to content overlap, was incorporated into a new version of the RAQ containing 16 items (RAQ-16) [Steffen et al., 1998; Ralph et al.]. The RAQ-7 is suggested for use to compare attitudes between groups, whereas the RAQ-16 or RAQ-21 is recommended for comparison within groups.

However, with limited subjects as in this case study, longer versions of this instrument may be preferred in order to gain more information about various concepts of recovery (personal e-mail communication, J. Steffen, July 24, 2009). Since the purpose of using this questionnaire is to capture a general view of a number of popular recovery beliefs within scientific literature, it is helpful to acquire as much knowledge as possible by using the longer instrument. Therefore, the RAQ-21 was chosen to reflect as many recovery ideas as possible which could potentially highlight personal perspectives of consumers and their families.

In addition, the researcher can reduce the 21-item questionnaire into two underlying themes while preserving the psychometric capabilities of the instrument, as was previously accomplished by its designers during factor analysis (personal e-mail communication, J. Steffen, March 22, 2010). This contributed to efficiency of data

interpretation, offering a strategy of compiling many recovery concepts into two themes. Also, one of the more useful aspects of assessing attitudes of consumers and families using the RAQ-21 is the ability to compare patterns or discrepancies between both parties.

### **Multiple Case Study Data Analysis**

Analysis for qualitative and quantitative portions of data aimed to describe the phenomena of psychiatric medication experiences and adherence, social support, and recovery in terms of themes that emerged from participant data. Preliminary analyses of both types of data have been ongoing in the course of interviews and verification calls, including the auditory review of interview tapes to this point. This section of the chapter will highlight the analysis process that included integration of qualitative interview data and recovery instruments for a comprehensive review of multiple case study data.

Although a variety of strategies exist for qualitative analysis, the approach chosen for this study was a compilation of generic descriptive methods for qualitative data by Creswell (2003), case study data by Yin (2009) and structured steps of qualitative analysis by Strauss and Corbin (1998). The reader is referred to Figure 3.6, which displays the steps of analysis as adapted from perspectives and guidelines offered by the aforementioned authors.

This combination of approaches was primarily chosen for the purpose of guiding the researcher in a stepwise progression that is organized and well-understood in terms of analyzing data for the current study, but also for any future replicated studies. Another important rationale for crafting this type of approach was to honor flexibility during

analysis, since the process of understanding emerging perspectives of participants is neither simple nor linear (Miles & Huberman, 1994).

To briefly reiterate, the most significant reason for the selection of this case study research design was to develop profound understanding of a perplexing multi-dimensional human issue. In reality, grasping the meaning of qualitative data occurs through a rather messy, iterative process of coming to understand the participant's universe as intimately as possible (personal communication, E. Carpenter-Song, April 8, 2010). So the design, as well as the analysis, of each case study must fit the desire to extract meanings as constructed by participants within their own lived experiences (Yin, 2009).

The researcher aimed to first understand the consumer perspective, followed by the family perspective. Examination of within case data was accomplished first, followed by synthesis across cases. Since the consumer was the primary case for this study, with triangulating viewpoints from family, analysis rightly emphasized the experience of the consumer foremost.

As displayed in Figure 4 below, the data analysis process included: a) organizing and preparing data; b) gaining a general sense of data; c) identifying themes and categories within data; d) conveying descriptive information; and e) interpreting data. So, the general direction of analysis was to initially understand the data in a broad sense and, as the researcher became more immersed, synthesize themes and relationships within the data (Creswell, 2003; Miles & Huberman, 1994; Strauss & Corbin, 1998; Yin, 2009).

Although analysis appears to be a logically organized chain of steps, it is very important to note that researchers will frequently not follow steps rigidly. Instead, the steps are better viewed as a guideline for progression of analytical thinking. For example, it is possible that during initial examination of qualitative data, a researcher may be in the process of labeling some phenomena while simultaneously categorizing or classifying other concepts within the data. This was certainly true for this study.

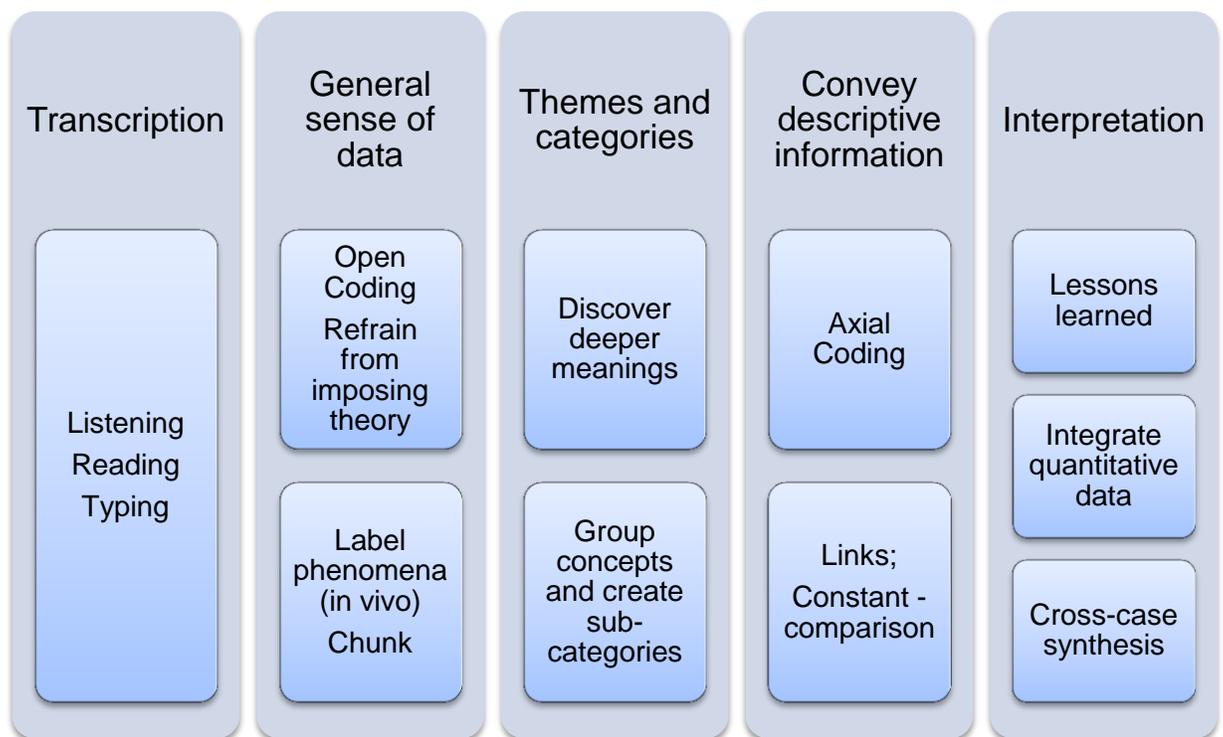


Figure 4: Qualitative Data Analysis

(Adapted from Creswell, 2003; Strauss & Corbin, 1998; Yin, 2009)

### **Phase One: Organize and Prepare Data**

Qualitative analysis began by organizing and preparing the data through transcription (Creswell, 2003). The foremost source of data stemmed from in-depth interviews. Due to the work load and responsibilities of the primary researcher, a

transcriptionist was hired as part of this process, maintaining professional confidentiality of research information. Spoken words of participants, as well as supplementary sounds such as crying, laughing, sighing, and pauses or delays were also included in transcription, as this information was useful in providing perspective relative to moods and general context of the interview.

As Strauss and Corbin (1998) proposed, it is more apt to treat each case separately in the beginning so that a researcher can build knowledge between cases, considering each case with a fresh pair of eyes. This allowed the researcher time to reflect on the data within each case study, noticing patterns and differences as well as omissions or gaps in knowledge. The researcher's primary focus was to understand the consumer's lived experience, utilizing family data to elaborate on their experiences.

Organizing and preparing the data also included the initial audio-analysis to prepare for verification follow-up interviews. The researcher listened to each participant's audio-tape, as well as reviewed the written transcripts as they became available. A written document was prepared by the researcher that included categorization of participant comments according to topic areas.

In addition, follow-up questions were prepared to address unanswered questions particular to each case. During the follow-up call, the researcher explained the purpose of the phone call; that is, to verify that the researcher accurately heard what the participant intended to say. Next, the researcher read through participant statements within each particular topic area, asking participants to agree, disagree, or voluntarily provide additional information as they saw fit.

## **Phase Two: General Sense of Data**

The second phase of analysis for this research involved gaining a general sense of the data, or open coding/ *in vivo* coding (Creswell, 2003; Strauss & Corbin, 1998). A primary feature of this phase is that the researcher becomes acquainted with the experiences of participants by noting particular concepts that are shared in the course of interviews, and consequently apply labels to these concepts or phenomena. The goal in open coding and *in vivo* coding was to freely label chunks of data as words and phrases were identified as belonging to a certain category (Strauss & Corbin).

Theoretical frameworks are a part of the researcher's pre-existing knowledge, as experiences of consumers and families permeate theoretical and practical ideas about dimensions of medication adherence. However, theoretical frameworks were not imposed on the emerging data during development of the coding system (Strauss & Corbin, 1998). Instead, the data were permitted to emerge from participants freely, whether or not it was supported by theoretical thinking processes (Strauss & Corbin). In Chapter 5, frameworks will be discussed in terms of contribution, rebuttal, or a combination of these to better understanding of participants' experiences (Creswell, 2003).

Initial labels changed many times throughout the course of analysis as codes were better defined and more was known relative to linkages of concepts. Open coding allowed the researcher to begin the process of understanding without yet being tied to definition, not quite with reckless abandon, but with a somewhat structured initial design

of the coding map. The labeled chunks of data were not particularly meaningful yet, but this step was necessary before moving forward.

Beginning ideas were proven correct or incorrect as more was understood whilst the researcher immersed herself in the participants' universe. The researcher, at this phase, was not concerned with right or wrong. Instead, the purpose of this stage was to merely gain an impression of the information presented by participants (Creswell, 2003). The main question asked by the researcher during this phase was "what is this about" (Creswell, p. 192)?

### **Phase Three: Uncover Themes and Categories**

While this form of coding is part of the process of interpretation, researchers must eventually move past labeling, delving further in-depth by performing microanalysis to examine the range of possible meanings (Creswell, 2003; Strauss & Corbin, 1998). This signifies the third phase of analysis as themes and categories were recognized. That is, through developing a sense of concepts that could be grouped together by characteristics and actions, categorizing became a natural step to discovering deeper meaning within the data. Categorizing is the equivalent of grouping concepts using more abstract terminology. Sub-categories were also envisioned as properties and dimensions of larger categories became apparent (Strauss & Corbin).

The purpose of this phase was to identify descriptive codes for groups of information that appeared in the text (Creswell, 2003). Although the researcher initially identified a large number of codes, it was necessary to reduce codes to a manageable quantity (Creswell). Collapsing large numbers of codes was a process that occurred as

the researcher wrestled with the meaning of information, identifying sub-categories that belonged to major categories (Creswell). Along with each code assigned to groups of concepts, the researcher was able to demonstrate the credibility of descriptions with supporting evidence from text (Creswell). Again, this process of coding first occurred within each separate case for consumers, family members and then across cases for consumers and families.

This phase called for the identification of an initial coding system, known as a codebook (Neuendorf, 2002) which helped to classify codes with concepts that emerged from the data. A formalized codebook for consumer data helped to structure ideas, all the while providing a sounding board for decisions as to where information fit. The coding system was developed only for consumer data, with family perspectives serving as an extension of the view of each consumer's social environment. Although it would have been possible to develop a coding scheme for families, it was not the focus of this particular research study.

The first codebook included concepts of the consumer's health management (including medication), health response (outcome), and the evolutionary process of discovering need for change and strategies for change. Initially, the researcher viewed the person's health management on a continuum that included aspects of autonomy, interdependence with supports, and dependence/vulnerability.

Although these concepts would prove illuminating later in analysis, it was decided that these constructs clearly reflected a heavy researcher viewpoint versus true

perspectives of consumers in the study. In other words, the researcher had to make a second attempt to extinguish theory further as she engaged in this stage of coding.

For example, when consumers explained their expression of medication concerns to their doctors, this concept was labeled “autonomy.” With further thought, however, consumers did not particularly believe in their sense of autonomy with this type of statement. In fact, they were simply stating that they performed the act of self expression with the doctor. As it turns out, the label of autonomy was a therapist assessment in the sense that self expression is theoretically part of managing ones health. In reality, the consumer was not really saying they felt autonomous doing this act. It was anticipated that the codebook would require revision.

As mentioned previously, a co-researcher became involved at this phase of research analysis. The goal of collaboration was to test the initial codebook as applied to case study evidence, identifying disparities and omissions through independent application of codes, and joining together to compare thoughts as attempts were made to revise the codebook.

Initially, the primary researcher met the co-researcher in person to teach the initial coding system. Concepts were applied independently to one consumer transcript before re-convening for discussion. During the meeting, it became a struggle to find concepts in transcripts, resulting in many gaps in the data. The initial coding system was not simple enough in language to capture what participants were truly saying. Instead, the mutual agreement among both researchers was that it contained too much theory, prematurely imposed.

Both researchers collaborated to describe and organize concepts and language that resonated more with how the participant actually talked, instead of how a therapist thinks. The primary researcher returned to re-development of the coding system independently. Once this was accomplished, both researchers collaborated by applying the revised coding system to another consumer transcript. Gaps in the coding system were again noted, although much less than previously. Alternating independent and collaborative coding continued until consensus was reached. The accepted codebook (Appendix N) included the following constructs: self, environment, performance, outcome, and change process.

Inside the *self* category, concepts included: a) self concept, b) self efficacy, c) life perspective, d) health perspective, e) medication perspective, f) change perspective, g) future perspective, h) support perspective, and i) illness experience. In the consumer's *environment*, concepts included: a) family, b) friends, c) non-medical mental health community, d) health care providers, e) society, f) economic, g) home, h) community, and i) properties of medication.

*Performance* components included: a) self expression, b) life behavior, and c) health behavior. Outcomes were inclusive of: a) do, not do, or sometimes do a life activity, b) adhere, not adhere, or sometimes adhere to medications, c) implement adaptation, and d) integrate lifestyle change.

Finally, the *process of change* included the following concepts: a) discovery, b) goal identification, c) trial and error, d) decision making, and e) exploration of ways to

adapt. This language was consistently applied to all consumers' narratives whilst noting patterns, discrepancies, theoretical support, and omissions/gaps.

#### **Phase Four: Convey Descriptive Information**

The fourth phase of analysis for this research study conveyed descriptive information using *axial coding*, which refers to the process of putting together data that has been broken down into categories (Creswell, 2003; Strauss & Corbin, 1998). The purpose of this phase of analysis was to determine how categories broke into subcategories, and how they linked with one another. In axial coding, relationships and associations among categories are exposed as researchers ask questions about why, how, where, or how come (Strauss & Corbin).

A variety of techniques were used throughout the entire coding process and for this phase in particular. By and large, constant comparison and selective comparison were the primary strategies used during this coding process. Constant-comparison is a means of repeatedly testing concepts and themes within the qualitative data (Creswell, 2003; Strauss & Corbin). For example, ideas that emerged during the coding process were continually reviewed using narrative examples to compare, contrast, replicate, or classify concepts (Creswell). In addition, the researcher kept notes on themes, ideas, patterns, and noticeable holes in the process of analysis (Creswell; Miles & Huberman, 1994).

Systematic comparison refers to the discovery of association among participants' data and experience or literature (Strauss & Corbin, 1998). Comparing a concept against

another source helped the researcher to identify what he or she was looking for, if the concept was unfamiliar.

### **Phase Five: Interpretation**

The fifth phase of interpretation sought to explore the lessons learned from narrative data, delving into the meaning of findings (Creswell, 2003). Thus, the process of comparison between research data and the presence of findings within literature and theories ensued.

In order to thoroughly examine data for this research, cross-case synthesis was an important step in determining the variability across cases (Yin, 2009). Visual models were imagined that reflected emerging evidence as incorporated through a thorough review of information across case studies.

#### **Cross-case synthesis: Development of a process model.**

Yin (2009) proposes that researchers choose analytic techniques based on the particular design of the study. Cross-case synthesis, where researchers aggregate findings across cases, is one of the strategies most appropriate for this research study. Of course, a major benefit to using multiple case study research is that it produces a large amount of data for comparison among people that are both unique and similar.

Thus far, a multi-step process of analysis has focused on data within case studies for both consumers and families. Sequentially, it is sensible to grasp the emerging perspectives of each consumer and each family member first and follow with an analysis

relative to what was unique and what was not. Moreover, the researcher was tasked with interpreting *why* patterns and differences may exist between cases.

To display a high volume of information for cross-case comparison, it was helpful to organize and view key pieces of data within a visual display using matrices (Miles & Huberman, 1994; Yin, 2009). They were particularly useful in reducing the bulky narrative data into a more accessible format (Miles & Huberman).

Matrices that proved to be most useful were those that centered on both consumer and family perspectives using key phrases according to the codebook. The cross-case comparison was a final step in analysis after each participant case was understood. Matrices permitted the researcher to assemble and view chunks of data so that shared and disparate themes emerged more clearly for comparison across cases.

Once themes were understood across consumer and family participants, analysis naturally progressed to the development of a process model. Process models incorporating consumer themes emerged through exhaustive analysis within and across cases, and highlighted the interrelated processes that surfaced for these participants. Although one cannot generalize from multiple case study research, it is hoped that grasping the meaningful experiences of these participants may shed light on the issue of adherence for others with schizophrenia spectrum disorders.

### **Quantitative analysis.**

So, missing from this elaborate ladder of analysis are the quantitative data provided by demographic and recovery questionnaires. For the purpose of chapter structure, they are discussed separately. However, they are only partially separate in

reality. It is true that subjective experiences are considered primary within each case study. As such, a decision was made to first seize profound meaning from consumers' and families' subjective experiences.

But quantitative measures were thought to be relevant pieces of data collection for this study, even if they were considered to be a much smaller piece. Since dimensions captured by forced-choice questionnaires are potentially valuable as a triangulating perspective, this section will outline how quantitative was converted to qualitative information for purposes of supporting or refuting interview data. Comparisons between both data sets inform whether perspectives match, overlap, or are inconsistent.

Because the number of participants in this study is quite small, parametric statistical analyses were not possible. Descriptive analysis was most useful, focusing on mean and range of scores on surveys. Each questionnaire was given a total raw score, followed by sub-scale scoring in both the Mental Health Recovery Measure (Young & Bullock, 2003) and the Recovery Attitudes Questionnaire-21 (Steffen & Wishnick, 1999). As described previously, the MHRM reduced to six subscales and the RAQ-21 reduced to two overarching themes.

Information gathered from questionnaires in this study was more akin to qualitative features than quantitative. Raw and sub-scale scores for only a few participants are merely useful relative to providing the researcher with a quick comparison of viewpoints toward popular recovery beliefs. In order to gain the full benefit of what questionnaire data offered, the researcher delved into descriptive waters,

closely examining perspectives participants offered within both narrative and survey sources.

The researcher decided which answers on surveys were suited to further analysis and discussion. Of course, surveys being what they are, the researcher avoided creation of meaning from objective data alone. In this study, it was only through the examination of subjective experiences that objective data could be used to elaborate upon themes. Therefore, participant answers were not merely viewed according to mere raw score, but were translated as appropriate to qualitative data. To assist the researcher in making decisions about what dimensions to include, bar graphs were a useful visual technique in analysis.

### **Summary**

This chapter provided an overview of methods for this study. The multiple case study approach was reviewed followed by a synopsis of study characteristics including participants, role of the researcher, procedures, and data analysis. The following chapters will report on results of the study and discussion of case findings as related to medication adherence, social support, and recovery for individuals with schizophrenia related disorders and their families.

## CHAPTER 4: RESULTS

Four consumer-family dyads comprised each case study. This chapter is organized such that each participant is introduced via brief vignettes, followed by results as related to research questions across cases. Results for consumer participants and then family participants are brought forth, highlighting thematic patterns and differences. The chapter concludes with a summary of findings that will be further discussed according to theoretical models of Person-Environment-Occupation (PEO) [Law et al., 1996] and recovery (Anthony, 1993) in the final chapter. Identifying pieces of information, including names and locations, have been changed or omitted to protect confidentiality.

### **Consumer Vignettes**

#### **Case One: Dan**

*Dan is a 33-year-old Caucasian man who lives on his own, works part-time at a grocery store, and has recently begun volunteering for his local NAMI. He was diagnosed with schizoaffective disorder approximately 15 years ago when he was hospitalized for his first psychotic break in adolescence. His parents divorced when he was a young boy, and he has one brother. His mother re-married several years ago, but Dan is not close with his stepfather. Dan visits with his mother frequently and they share a vehicle together. His father lives across the country, and he is slowly rebuilding a relationship with him after years of emotional distance. Dan is what many providers would consider “the good patient,” reliably taking antipsychotic medication since the onset of his illness. As his case will illustrate, though, he does not take medication lightly, and has many thoughts related to this topic.*

Dan met the researcher for two in-person interviews and one in-person meeting for verification purposes in March and April 2011. For the first interview, Dan met at the library but was late due to traffic. Most of the interview took place in the researcher's vehicle. Dan was anxious and guarded initially, but his tension eased as he got to know the researcher and shared about whom he was and what was meaningful to him. The second interview took place at Dan's basement apartment since there was difficulty coordinating the schedule for use of the vehicle that he and his mother share. The third interview was brief for the purpose of verification, and was also completed in his apartment.

#### **Case Two: Rebecca**

*Rebecca is a 35 year-old African-American woman with schizophrenia who is temporarily living with her parents. Although she was first diagnosed with ADD and depression in her early adulthood years, the illness symptoms progressed to include psychosis. This eventually led to the diagnosis of schizophrenia approximately 5 years ago. She has experienced challenges with medication adherence, particularly because of disturbing side effects and non-efficacy. It was not until her voluntary hospitalization in a research setting that Rebecca tried and found a medication that she feels is right for her. Rebecca was born into a family of entrepreneurs, and thinks about ways that she can market her creative items in the business world. She is keenly aware of her family's accomplishments in their work. She was recently awarded SSDI benefits, and hopes that she can return to her now empty condominium given her improved financial circumstances. Rebecca and her family are known to the researcher from a previous clinical relationship.*

Rebecca requested to have one longer interview rather than two. However, she developed a headache in the midst of the meeting, and it became necessary to add a second interview. For the first evening meeting, she solidly expressed a desire to meet at her mostly empty condominium, and was given a ride by the researcher. After assisting the researcher to parallel park in the city and ascertain parking regulations, she showed the researcher to her place. A small loveseat and a folding chair were available in her living area. After the interview, she was given a ride back to her parents' home. She wavered about whether she could continue the interview given her headache, and offered to continue the meeting in the car. However, the researcher encouraged her that it was not necessary to proceed while not feeling well.

The continuation of the interview took place a few days later at the home of her parents. She was not at all considering meeting at her condominium again, possibly given her thoughts of parking limitations based on the last experience, although she did not elaborate as to why. She did, however, seem comfortable meeting at her parents' home given that they were both out of the home working, expected to be gone for much of the day. Rebecca was more expressive during the second interview, potentially because it was earlier in the day than previously, and she was feeling well without a headache. Her verification telephone meeting occurred several months later in August 2011.

### **Case Three: Sean**

*Sean is a 35-year-old black male who is living in his own apartment after a long period of homelessness. He was diagnosed with schizophrenia at the age of 20 while in jail for a misdemeanor. Sean endured numerous cycles of homelessness, imprisonment,*

*and hospitalization as a result of symptoms of his illness, which included prominent paranoia and auditory hallucinations. His symptoms often led him to act bizarrely and engage in verbal and physical altercations with family, corrections officers, and other members of society. Before Sean was eventually put out of his father's home for his disruptive behavior, he had endured many attempts to take care of himself, work, and trial psychiatric medications. However, until fairly recently, Sean was not successful in adhering to his medication for long periods of time, disgusted with considerable weight gain. His transition to medication adherence ensued when he had his last cycle of imprisonment and hospitalization in 2008. It was then that he promised himself and his father that he would make a commitment to try and get better. Sean was awarded supplemental security income (SSI), and is currently exploring work options. He utilizes bi-weekly psychosocial therapy and monthly medication management for the past 2 ½ years. His primary family support continues to be his father, who participated in this study.*

Sean participated in one main in-person interview in May 2011 and a verification phone call in October 2011. Sean responded openly to questions asked of him by this interviewer, not appearing guarded and seemingly enjoying the process of sharing his thoughts about psychiatric medication. To review, the codebook included concepts of self, environment, performance, outcome, and change process. Sean addressed each of these concepts in his narrative, but he seemed to focus on particular aspects as they relate to his eventual transition to medication adherence.

**Case Four: Alison**

*Alison is a 34 year-old woman who is diagnosed with schizoaffective disorder for the past 15 years. She has recently married and lives with her husband in an apartment. Alison has worked full-time for over three years at a public library in the children's section. She grew up having been exposed to severe mental illness every day, since her mother suffered from bipolar disorder and her father from schizophrenia. As a young child, she endured the traumatic experience of losing her mother to suicide. When Alison became ill in her early twenties, she took medication but had a brief experience of non-adherence that resulted in a relapse of symptoms. Her father and brother worked very hard to keep her out of the hospital, which they were successful at doing by keeping her supervised at her father's home during periods of crisis. Her father went so far as to sign her up for a pottery class in the community to mimic the occupational therapy he had received when he was hospitalized! As her case will illustrate, she has decided to take medications for her illness, but struggles each day with ambivalent feelings of gratefulness and anger about needing to take them.*

Alison preferred to meet for one longer interview, as she explained when the researcher met her in-person at a local drop-in center. She was present to hear about the potential research opportunity, and brought her husband and dog with her. Alison immediately expressed interest, but stated that she was hesitant to meet at the drop-in center as she did not know many people there and rarely visited. After attempts to secure a private library room proved unsuccessful, she agreed to meet in a private room in the drop-in center. She provided transportation for her father for his interview, as he did not

drive. He waited in the center while Alison had her interview first. Alison's final interview was by telephone for the purpose of verification in October 2011.

### **Consumer Experiences with Medication Adherence**

Resultant themes emerged in the analysis of narrative data across consumer cases regarding medication adherence. Two such themes are foremost in consumers' experiences of medication adherence, including: a) self-awareness through oppressive discovery, and b) permeation of fear and insecurity around medications.

#### **Self-Awareness through Oppressive Discovery**

Consumer data revealed their continual discovery of ways to take care of themselves, including use of medication, as a process rather than a distinct point in time. Developing self-awareness was evident as consumers engaged in the process of discovery and change around medication decisions. The timing happened differently for each person, as evidenced by decisions to adhere to medications early or later in the illness continuum.

A primary view of each consumer's discovery process was acquired in the analysis of their transitions in commitment to medication. This process included various aspects of self-awareness and self-development in the management of their mental illness, as illustrated in Figure 5 below.

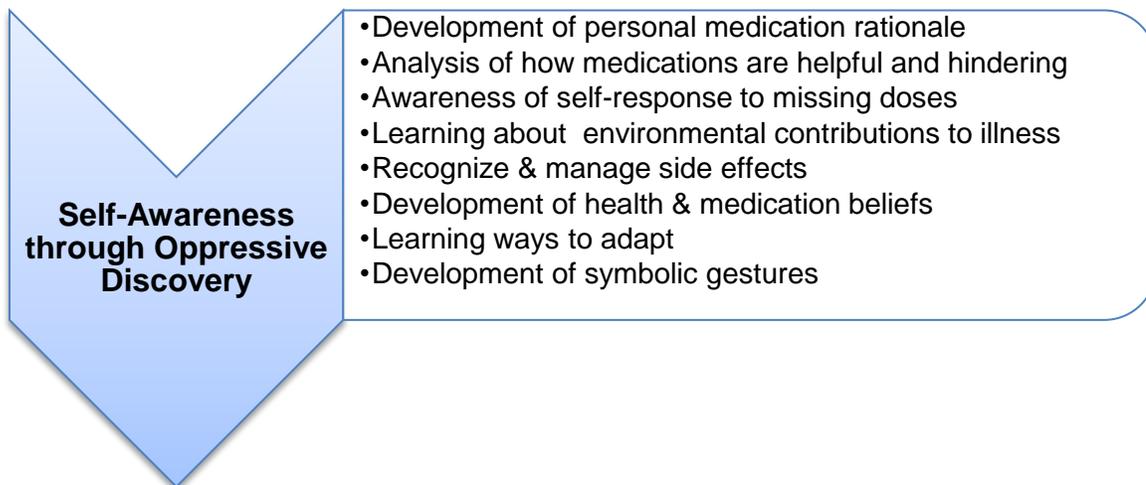


Figure 5: Self-awareness through Oppressive Discovery. This figure illustrates features of self-awareness development through stressful trial and error experiences managing their serious mental illnesses.

Two consumers with schizoaffective disorder, Dan and Alison, were largely adherent to medication for much of their illness courses. These consumers still contemplated non-adherence to medication as they endured harsh symptoms and side effects of medication. Two consumers with schizophrenia, Sean and Rebecca, underwent a more obvious transition in medication commitment through periods of non-adherence. They shared much about their discovery processes during the course of the interviews.

#### **Development of a personal rationale for taking medications.**

Each consumer in this study, no matter where they were situated on an adherence continuum, communicated a unique rationale for why they decided to make the choice in favor of medications. As previously alluded to, some consumers readily decided to take medications sooner than others. Nonetheless, they all faced challenges in the process that did not make the decision an easy one.

When Dan was diagnosed with schizoaffective disorder in the hospital, his initial change process relative to accepting medications appeared to move rather swiftly. He decided to take medications against all odds in the face of opposing viewpoints within his social support system. Since his dad did not agree with the path of medications, and his mother and doctors did, Dan had some decisions to make. Dan illustrates that a swift decision does not mean a hasty one and he did not take it lightly. In his case, the realization of frightening psychosis and his desire to move on with a productive life catapulted him into acceptance of medications, and what would lead to continuing commitment to them no matter what:

Dan: *“[My father was worried about the side effects of medication.] But I was kind of like, well, I didn’t feel well, so. I wanted to get better.” (1/p 19)*

*“[I decided to take medication] pretty quickly, even though it wasn’t...it was a difficult decision, but I mean I figured these things could do pretty, do some pretty big damage, but you know I’d rather not have the psychosis or whatever.” (2/p 15)*

Dan’s analysis of the costs and benefits of medication were a part of his initial thought process as he contemplated whether or not to take psychiatric medications for his illness:

Dan: *“I was worried about the long-term effects of medication, but when that was put up against long-term effects of being mentally ill, I decided that medication would probably be better.” (2/p 15)*

In the context of his decision for medicating, he also considered that other people must be dealing with challenges similar to his own:

Dan: *“I think when I realized that there were other people, like, this is a common, this happens to people, that was relieving. But it was also kind of depressing in its own way. It was relieving like, I’m not like a martian or something (LAUGH)! But, oh, well, I’m disabled so.” (1/p 20)*

*“So I figured okay well, long-term medications have been proven to work for people so I might as well try it.” (2/p 16)*

*“Yep, well, there were other kids that were having similar problems too. I think I talked with them and you know it started to be more common for kids to go into the, and have mental problems or need medications or something. You know people would get ADD or bipolar or whatever and take medications for them.” (2/p 19)*

Sean, who was homeless for several years, did not experience an expeditious acceptance of medications. But his data reveals that he did, indeed, undergo a palpable and seemingly gradual change process that finally led to his decision to take medications. For many years before and during his homeless period, Sean would feel forced to take medication in jail or the hospital, experience side effects, and immediately discontinue medication after discharge:

*Sean: “Well, I was in the hospital, I was taking medication because I had to, but once I got out of the hospital, not so much. Every time I’ve gone into the hospital, there’s been some like physical changes. I’ve gained a lot of weight and you know, I don’t know if that was the medication or just sitting around all day, but part of me didn’t like the feeling of medication that I felt as if my senses were being dulled like you don’t have the same mental sharpness as you would have if you weren’t taking medications.” (P122)*

Sean vehemently expressed his perspective of growing tired of repetitive cycles of incarceration, hospitalization, and homelessness:

*Sean: “Part of it would be I guess you just get tired of going through the same thing over and over again. You go to jail, you go to the hospital, you go to the shelter, and you just go through the same cycle over and over again...”*

His circular course finally found a detour. Sean goes on to explain what happened at the end of his repetitive cycle that led him to voluntarily commit to treatment:

*Sean: “The last time this happened, it was pretty much the same thing. I was on the street, and just went up to this guy and I hit him for no reason, for no reason at all...So the police they brought me to jail, they let me go. When I missed I court date, I didn’t really pay it much mind, but about a year later I got picked up for something else and then I got sent back to jail, then I got sent back to the hospital. I was taking medication obviously and once I got out of the hospital I made a promise to myself and I made a*

*promise to my father that I was going to try to seek out help of some sort. I had heard something about NAMI Connections or something like that and I said all right, I was going to try to go to a meeting.” (P200).*

Of particular note, Sean finally began treatment with Risperdal given to him in sample packs by his providers. However, at one point they ran out of samples and had to switch him to Geodon. With luck, he responded well to this medication just as he had to Risperdal.

Although Rebecca always had supportive housing, she also took more time to discover a fit for the right medication. Like Sean, she contemplated for years about medications. This occurred during the process of trying on different diagnoses and medications, usually without success. Therefore, her resolution to eventually adhere was not an effortless course. Her process of change involved a discovery that her first attempts with antipsychotic medication were less than desirable and perceived as harmful. In response to unsuccessful experiences with medication side effects and poor efficacy, Rebecca made a change in the direction of non-adherence:

*Rebecca: “Well, the medicine was really not working and it was making me miserable, so I mean it’s like you don’t just keep taking something if it’s not working for you...No I just couldn’t. I mean I was so sick. I could not take it, because I knew that it was disrupting my system. Yeah, yeah I mean it’s like when you’re really sick and you take a medicine and it makes you throw up, I mean that’s kind of how it was.” (p 38)*

Although she was experiencing negative side effects and was not feeling better on her initial medication, she felt pressure from her family and friends to continue taking the medication:

*Rebecca: “Well, I mean, I told [my mom] I wasn’t taking it. It wasn’t the right medicine for me. [Her response was] that ‘you need to take it.’” (p 31)*

Likewise, a friend chimed in without invitation:

Rebecca: *“Yeah, I had a friend who said you know ‘don’t stop taking it if it’s not working for you. It doesn’t matter because the doctor prescribed it.’ And that’s not helpful. You know I need somebody to say ‘well, what’s one of the problems? Ok, maybe the doctor can prescribe something else.’ And so you know, that type of stuff is not helpful and sometimes you know when my mom was trying to make me take it too, you know that wasn’t helpful either.”* (p 37)

More recently, she describes finding a balance with her current medication, which she started taking during her voluntary research hospitalization:

Rebecca: *“Um, I think of when I was at [the research hospital] and how it, well it was an obvious you know recovery. Because there was a time when I felt really out of balance and then I felt much stronger. And so I feel like I’m getting stronger and stronger and I feel like you know, I feel like myself again...”* (p 41)

Alison dabbled in non-adherence with her antidepressant medication at one point in her life. Although she expresses ambivalent viewpoints about her perception of whether this time period was one of happiness or misery, she illustrates at points during the interview that it was a stage that she would not like to re-visit:

Alison: *“[I went off medication] only once. Only once, and that’s when I had my nervous breakdown. And I was taking Prozac pretty regularly and then something told me not to take it anymore...Whoa, big nervous breakdown.”* (p 30)

As she demonstrates in her interview, Alison’s reflection that changing her commitment to medication was wrought with a mixture of pity and gratitude:

Alison: *“No, I don’t know, somebody told me to [take the medications again]. I wish I wouldn’t have...because it sucks...I wish I didn’t have to take something that makes me a different person [crying]...It’s what everybody wants.”* (p 33)

But, when she considers her mother’s tragic outcome, she concurrently feels appreciative:

Alison: *“[CRYING] I can’t remember. I’m upset that I hadn’t been sick when...just since being an adult. And that makes me sad too. Yeah, and I’m pretty lucky that they have these medicines, you know... Yeah, because my mom didn’t have any medicine and she killed herself... Yeah, she didn’t like Lithium...but had she have hung on like three more years [CRYING], you know, they might have had something for her.”* (p 35)

### **Reflection of how medications are helpful and hindering.**

Consider the following quotes from consumers regarding their analysis of how medications are helpful in managing symptoms of schizophrenia spectrum disorders:

Rebecca: *“I guess, you know, a lot of [symptoms] have already improved. So, I think you know like paranoia and feeling that people are talking about me and that type of thing in a negative way...I think that’s more self-esteem...I think I still have some work to go.” (p 12)*

Dan: *“Um with the first week that I took it, it was pretty powerful, it like flushed out my whole system, you know, I don’t know. It wasn’t easy to take, but, yeah...[Clozaril] is more powerful...Clozaril has been able to, over the last year or so, it’s been able to kind of like eliminate symptoms. I don’t know how it does it. But it works well...sometimes I don’t hallucinate at all...I think beforehand I was moody. This I think I’m more stable, my mood is more stable. My thoughts aren’t as fast. Um, I’m not as paranoid...I think it’s helped with both [positive and negative symptoms] yup.” (1/p 15)*

Dan also compared efficacy as he analyzed his response to two different antipsychotic medications:

Dan: *“Over time [Zyprexa] wasn’t as effective as Clozaril. Clozaril is also a long, it keeps acting as time goes on so, its full effect doesn’t happen over 6 weeks, it’s well still happening.” (1/ p 16)*

Alison tended to view her medications as helpful in managing symptoms enough that she can work. She introduces a caveat here in that her work life is not made problem-free by medications:

Alison: *“Yeah, [the medications] help me work, which gives me some sort of standard of living. They kind of tone down the paranoia a little. I mean not completely because I am still discriminated against at work...” (p 15)*

She does, however, believe that medications have helped her to be more socially accepted:

Alison: *“Um, it’s helped me fit in more, you know.” (p 29)*

Rebecca also highlights the advantages of finding a medication that works, does not have side effects, and that helps her engage in life:

Rebecca: *“[What is helpful is] having a medicine that doesn’t give negative side effects because I think I was feeling paranoia and what have you because of Risperdal. I think that was a side effect in the Risperdal too. And so, having a medicine that really works makes you excited about taking it. I feel like I can do normal things again; being social, yeah being productive.” (p 35)*

On the other hand, Sean only believes half-heartedly in the effectiveness of his medication, owing at least part of his symptom reduction to housing:

Sean: *“Why, I don’t hear voices or anything like that, but I don’t know if it’s all medication. I know that medication is part of your wellness, but you know, there’s other things too. Like, if I was living on the street and I had a breakdown, that wouldn’t be surprising. But you know I have a space of my own, so that changes things somewhat.” (P254).*

Consumers also regarded their medications as hindering in some ways. Alison explains how remnants of her illness, the debilitating lack of energy and drive, are not helped by her medications:

Alison: *“Oh, that’s spending a lot of time thinking about things that I should be doing that I don’t have energy or mental know how to do. Like mop the floor, you know. I spend a lot of time thinking about mopping the floor but then I never get around to it or I don’t feel like doing it or I don’t know how exactly to go about it, so I just kind of put it off, you know...I wouldn’t say [I feel] guilty, I’d say more just kind of like a failure, you know that I can’t get around to doing it you know.” (p 15)*

Dan explains that, for a time when he started a new medication, increased anxiety and psychosis would seem to follow after taking the medication meant to reduce these very symptoms:

Dan: *“Well I noticed that after I took my medication, I’d have symptoms, pretty severe symptoms ...so after every time I took my medications, I’d have horrible panic and I would really be going out of my mind. I would start hearing things in the background, but other times I would get euphoric and I would think that like just weird things like there beings around me that I was talking to and that there was some....like every day I woke*

*up I thought like a different thing was happening like it was pretty much nonsense. I didn't know what was going on, I was talking to things that I....that weren't there... But I didn't really have any choice, I figured okay well I could stop taking medication, but that might be even worse..." (p 1-2)*

Rebecca viewed the main hardship of medications in her experience to be unwanted side effects:

*Rebecca: "It was only challenging [to take medications] during a period of time when the medication wasn't working for me and I had a lot of really bad side effects. Now it's not really challenging." (p 33)*

### **Awareness of self-response to missing doses of medication.**

Two consumers, Dan and Alison, explained a part of their discovery process was learning how their bodies respond to missing doses of medication accidentally.

Dan has learned the hard way about his manic response to missing doses:

*Dan: "Do you mind if I, it's strange because I always wonder like why wouldn't people take their medications? I don't know, I guess I just see it as an illness...If I miss medications for a day, I'll probably stay up all night, have emotional roller coasters...have racing thoughts, won't want to go out and meet people, so if it's, if I do that by accident once, for one day, I'm thinking okay if I do it for two days, then you know it's going to get even worse..." (2/p 28)*

When Alison unintentionally misses a dose, she almost immediately experiences mood, cognitive, and psychomotor worsening:

*Alison: "Usually I start feeling like shit... In the morning, I feel like very depressed and the afternoon, if I forget my morning medicine. And then if I forget my night medicine, the next day I can't really dial the phone, it takes me several tries to dial the phone, you know, and on the computer, my fingers won't really work that well on the computer and I just have to work through it and then take it the next night you know." (p 44)*

### **Learning about distinctive environmental contributions to illness.**

Self-awareness of influences that may contribute to the appearance or recurrence of illness symptoms was a commonly discussed aspect from each consumer's point of

view. Of course, much of their reflection occurs in hindsight. Dan placed the onus of his illness relapse on a multitude of environmental influences:

Dan: *“It was a combination of a lot of things. Um, I had family problems, I had a stressful job. I was you know living with my mother and stepfather which wasn’t very easy. Um, I didn’t have a group of friends...they were trying to change medication because they had the new generation of drugs out for psychosis and depression and mood...so I got a complete change in medication and then I got a job...I was transferring my therapy from public to private. And also the therapist and the psychiatric nurse that I was getting treated with left the place that I was getting treated...” (1/p 12)*

Alison wondered how economic impacts may have played a role in her illness:

Alison: *“I think maybe if I had a better life, I wouldn’t need medication at all. Like more money. Like more prospects, more, a better real estate situation....maybe I wouldn’t have had this illness...it’s part of it. I wouldn’t say it’s 100%, but it’s part of that.” (p 55)*

Once again, Sean reflected about the absence of the basic support of having a roof over one’s head in order to ward off symptoms of mental illness:

Sean: *“I wouldn’t attribute everything that’s happened in my life to taking medicine. I mean, because there’s other things in play. Like you need a place to live...that’s just as important as or maybe even more important than taking medicine because if you don’t have a place of your own then it doesn’t really matter what you’re taking really.” (p 272)*

Rebecca focused on the limitations posed by her social environment:

Rebecca: *“That’s when my mom was trying to get involved, and this just was not a good situation...She was just trying to get me to take medicine, you know. She wasn’t thinking about the other stuff...[And I said] ‘this isn’t working. I was like it’s not working...’ [I went to the doctor and said] this is not a good medicine for me...’ She shouldn’t have been involved...I was doing much better when I was working with my doctors independently.” (p 27)*

### **Learning to recognize and manage side effects of medications.**

Part of consumers’ development of self-awareness came through management of side effects that accompanied trials and continuation of medications. One of the foremost complaints, experienced by three out of four consumer participants, was weight gain as a

result of taking antipsychotic medications. It was apparent that their concerns were reality-based as these three consumers did, indeed, appear to be overweight. Their comments were frank concerning weight gain, sometimes filled with emotion. Dan is the only person in the study that did not bring forth a concern about weight gain from medications. He appeared to be of average weight.

Through tears, Alison shared how weight gain has affected her sense of self:

*Alison: "When I first started taking this medicine, I was 130 pounds, okay [CRYING] I'm 240, I've gained over a hundred pounds! Can you imagine going to a high school reunion having gained a hundred pounds, over a hundred pounds? I mean people talk about you, you know. It's disgusting." (p 46)*

She explained the experience of feeling hungry on her medication:

*Alison: "It's very tough, especially taking medicine, it's very tough... Because the medicine, I've been told it's not that it makes you gain weight, it just makes you hungry, so you feel like eating. You only want to carbohydrates, you know. (p 11)*

When asked whether her trials of various antipsychotic medications were different from one another, she again focused on the side effect of weight gain:

*Alison: "Not really. They all make you gain weight, they say they don't, but they're lying, and I just feel terrible being fat, but there's no other way. It's either fat and docile or crazy and skinny...I know I have to be fat and docile, and I have to be a sheep you know; stupid." (p 35)*

She was certainly not alone in her concern over weight gain. Sean also centered on the difficulties around gaining weight on his medication, and the no-win situation of choosing emotional over physical health:

*Sean: "Yeah, I mean like I've been hospitalized three times; and every time I've been hospitalized, I've gained like sixty/seventy pounds, and then maybe two years would go by and I would lose it, and usually it was because I wasn't taking any medication. And like this last time, when I got out of the hospital, I gained a bunch of weight and I haven't lost anything and I've been taking medication consistently, it may not all be medication, it might be that I have....I'm sedentary, I guess you know like I haven't like working*

*steadily or anything like that. I mean, I wouldn't say it's all medication, but a lot of it."* (p 15-16)

He goes on to explain that an advantage to homelessness and not taking medication may be the ability to stay physically fit:

Sean: *"Well honestly [the weight gain] might not all be medication. Because there's nothing good about being homeless, right? But I used to do a lot of walking and when I was homeless in New York City; I could walk the length of Manhattan maybe three times in a day and I walked the length of Manhattan like maybe two or three times, then play basketball and you know.... I mean, I did a lot of walking, I was a lot more active physically then I am now. Yeah [I wasn't taking medication]. You know, so I would like to have physical health and mental health and not have like one or the other."*

Other bothersome side effects were also discussed by consumers. On a previous antipsychotic medication, Alison expressed despair over a side effect involving her endocrine system, a pituitary tumor which stimulated prolactin production in the absence of pregnancy or childbirth:

Alison: *"Well it gave me a little thing on my brain [CRYING] like a microadenoma... Uh-huh, and it made me lactate...That was pretty gross."* (p 35)

Rebecca dealt with a few disturbing side effects when she trialed Risperdal. One that she found most difficult, as it linked with her life desire to have children was the disruption of her regular menstrual cycle:

Rebecca: *"And it changed my menstrual cycle too...I thought that this was really strange, unnatural you know."* (p 40)

She also dealt with nightmares and hallucinations:

Rebecca: *"Well I think there were a couple of medicines that really occurred negatively with my system. I was having really bad nightmares, things, you know, and hallucinations and it was just terrible. So, you know, the Abilify is much better medicine for me; at least for me anyway. I guess it affects people different ways."* (p 16)

Dan noticed the strange phenomenon of side effects that include worsening of existing symptoms that are an aim of the treatment in the first place

Dan: *“I’ve noticed that some medications, a side effect of some medications is actually psychosis, so it seems strange that the cure would also be the cause or whatever.” (2/p 28)*

Dan compares his previous medications with his current regimen. It is obvious here how Dan holds out hope for his Clozaril to work, willing to tolerate the horrible to get to the better:

Dan: *“[The Clozaril] actually had a difference....Uh, when I started feeling better? Um, well actually, I remember having the symptoms. Uh, like I remember having pretty intense symptoms, thinking like ‘Clozaril is a heavy drug and it’s horrible but (laugh) it’s gotta do it! I just had to believe that it would actually help me out, so.’ (1/p 16)*

Sean shared his experience of losing his cognitive edge in addition to weight gain:

Sean: *“Weight gain, Geodon, side effects with that one... Kind of like dull thinking, like it takes me longer to comprehend things... So I mean I don’t like the trade off as far as like not hearing voices and gaining seventy pounds, that’s not good...the weight gain that’s not good. I’m going to have to come up with some kind of way to get myself in better shape... I don’t like the way I look.” (p 27-28)*

### **Continual development of health and medication beliefs.**

Consumers also related their rationale for taking medication through expression of their health and medication perspectives (*Table 3*) which were also a process in the making. One way that health perspectives seemed to arise was through the course of time with illness, noticeably developing from the beginning and throughout their experience with managing the illness. Dan’s first reaction to his illness and medication provides some understanding of how he may have perceived the effect of the illness on his life:

Dan: *“Yeah, well, I think at first it was devastating. But I got myself going again. I wasn’t thinking, I thought I’d be fine for pretty much the rest of my life because you know I had a lot of support and I was on medications and stuff like that, so.” (1/p 9)*

Alison also reflected back on when she was first asked to take medication for her illness:

Alison: “*Uh, yeah, that was like the end of my life.*” (p 46)

Table 3

Consumer Health & Medication Perspectives

<b>Consumer</b>	<b>Health Perspective</b>	<b>Medication Perspective</b>
<i>Consumer 1 Dan</i>	May have to deal with symptoms forever; health would be worse without medications	Not to be taken lightly; worry about long-term effects; best hope out there; hope it helps; afraid it will stop working
<i>Consumer 2 Rebecca</i>	Desire to be healthy and balanced; schizophrenia is not eternal	Medication should not create side effects that interfere with life goals; medication should work; medications that help are exciting to take
<i>Consumer 3 Sean</i>	Desires physical and emotional health, not one over the other; may have to deal with symptoms forever	Medications help, but other things are more important like housing; desires a way to manage the weight gain
<i>Consumer 4 Allison</i>	Catch-22 of emotional over physical health; illness is only part of life; spends energy trying to care for self	Feels forced to take medications to fit into society; grateful for medications

Through living with the illness over time, one can sense a development of consumers’ health and medication perspectives. Dan illustrated an obvious continuation of weighing costs and benefits of antipsychotic treatment:

Dan: *“Let’s see well, I guess it’s just something I just accept as something I have to do...I guess I’ve been taught that it’s an illness like any other illness that has to be treated. I think it does help to take medications even though maybe in the past it might have been destructive, but I mean I don’t really, I mean I think it would be worse now to not take the medications.” (2/p 1)*

When asked whether he was in control of his choices, Dan agreed that he has been in control overall. He relates this ability with his developing self-concept:

Dan: *“I think I probably have a better idea of what kind of a person I am.” (2/p 22)*

Alison also tended to modify her outlook when she compares her initial thinking with her current beliefs:

Alison: *“Yeah at first I really didn’t want to take it. Now I just feel like I have to take it. I feel like it’s part of my job.... [To] take care of myself, you know. (p 43)*

Rebecca’s health perspective relative to aspects of life that are within and external to one’s control emerged:

Rebecca: *“Well, I think some things are out of, you know aren’t necessarily in your control. So you know I think the best thing for me to do is try to be as healthy as possible...” (p 11)*

An aspect of control that Sean has tried to hold strongly to is his desire to take the least amount of medications needed:

Sean: *“Honestly, I would prefer to take as few medications as possible. I don’t want to be taking like a hundred different pills and stuff. Like if I have to take one pill, that’s fine, but I don’t really like taking more than one.” (p 16)*

He goes on to illustrate an example of how he believes doctors give too much medication:

Sean: *“I don’t know. I think medication has its place, but I think there has to be other ways of managing your illness too. Like I think sometimes too much of a focus is put on medication and stuff and people are given too much medication, because I was in the doctor’s office the other day and I was talking to a woman and she was like ‘well, my*

*doctor put me on this medication and I was tripping over myself and I could barely function and I was running into things. People thought I was high on drugs ' and she was like the side effects are just terrible. The side effects were worse or almost bad as the illness itself. So that's one of the things that makes people not want to take that much. ” (p 22)*

Rebecca expressed a similar reluctance to taking too many medications, as she reflected on her upbringing:

*Rebecca: “I don't like taking a lot of medicine, but when I first started getting my menstrual cycle, I started taking aspirin, Advil, yeah...I think you should only take it if you have to. You know, you don't want to get addicted to medicine or any type of drugs.” (p 24)*

### **Learning ways to adapt.**

Consumers continually explored adaptations to manage their illness. Notably, they did not solely focus on coping with the illness. Rather, this aspect of self-awareness through discovery dealt with consumers' thoughts and actions associated with learning how to take care of themselves. Many adaptations that consumers utilized in their lives centered on other life occupations that are not necessarily viewed as a health activity. For these consumers, it seemed these life occupations had circuitous effects on health, presumably without their conscious awareness of it.

Adaptations could include practical ways of approaching a challenge, as well as changes in perspectives regarding health issues. Adaptations did not always directly link with medication, but in living life with illness. Very often, adaptations in their lives were not only seen with changes to medications, but in their reactions in the way they perceived events or via the tactics they used to perform life activities.

Sean had a significant and lengthy experience with non-adherence to antipsychotic medication. Interestingly, he illustrates here that he was always exploring ways to heal himself, even when he was experiencing severe symptoms:

Sean: *“No, my father put me out and he is like, he said that I was too much of a strain. I don’t know maybe my behavior was too much for him to deal with. So I became homeless and I was in....I was homeless for like maybe 2003 and 2002 and I started to try to like....on the inside I knew something was wrong, and I was trying to find ways to like heal myself; which is hard to do... So I kind of like I started seeking out religion, hoping that this would make me well and it worked for a little while, but you probably....you need to have other things....you need the healthcare in addition to like religion...Well, the religion I chose was Buddhism, which is kind of typical you know, given my personality because I like to go against the grain and you know I want to be distinct, you know I don’t want to be what everybody else is doing...But the biggest reason is that like you have exercises like karate or yoga and stuff and it made me feel better like when I did certain movements and stuff, I felt better, you know. I felt like I could function better and you know that was like the attraction and stuff.” (p 11-12)*

Sean went on to explain his trial and error approach, indicating that Buddhism has taken enough hold to keep his interest for the time being, but is not necessarily integrated yet:

Sean: *“I mean there’s a temple that I joined that I made a commitment like maybe seven months ago and I’ve been pretty diligent in terms of practice. Like I have been chanting in the morning and chanting in the evening. I honestly don’t know if there’s any benefit, you know, I’m just saying words that the priest tell me to say... I’m just kind of like doing trial and error right now seeing if I can find something that makes sense to me, you know, but like the exercise stuff used to make me feel better and there was a point where I was like obsessed with exercise, not now obviously, but I used to...”*

Rebecca explored ways to adapt to her weight gain, including modifying her emotions and outlook:

Rebecca: *“Um, yeah I mean it’s....life is easier when I’m slender... Because I can fit into my clothes a lot easier. So that makes planning a lot easier... Well, I try not to get too upset because I know that it’s partially because of my medication that I had gained weight. So right now I’m just trying to be a little understanding with myself and try to lose weight gradually.” (p 2)*

Dan found that, although he loved playing his guitar, he became over-stimulated by doing it. This led to his being fatigued the next day when he tried to go to work or school. He chose to modify this occupation in response to its negative consequences:

Dan: *“I haven’t played guitar in awhile because sometimes it over stimulates me and stuff like that...I was very like uh passionate about music. It wasn’t like uh I was doing drugs or anything like that. But I would get in, it would be a very, sort of creative experience where, um, I don’t know how to describe it but it was very intense. I often like forgot the time (laugh) so I could have actually been writing and recording music for something for hours and hours and then looked at my watch and said, “Oh, it’s 3 am, I have to go to work or school tomorrow or something like that...But it was, you know, it absorbed all my attention so, and it was very intense. And, when I improvise, it’s also a very exciting experience. So, it might be like, I don’t know, maybe taking, like, having a lot of caffeine or something like that (LAUGH)...Sure. It feels good, but after wards, it’s also kind of disorganizing I think. So, I might be off in a musical world, but then it’s kind of like, “Dan! Uh, you got to do this, uh, what are you doing, this, blah blah blah.” So, it would be, yeah, disorganizing. Uh, sometimes I wouldn’t be able to go to class, or something like that. Or I’d be tired at work.” (1/p 7)*

During her interview, Alison revealed ways that she incorporates the exploration and integration of adaptations, such as taking breaks at her job as a children’s library associate:

Alison: *“Yeah, that’s why I had to take a break because they get on my nerves, when I know, I take a break like this about once a year when they’re really getting on my nerves, I know that I have to take a break, because I really like the kids, they’re really nice, you know, most of them, they can’t help it that their parents are crack addicts and stuff like that. They can’t help it, you know, they’re just trying to make their way in the world.” (p 59)*

Interestingly, Alison also has incorporated avoidance of activities that cause her discomfort or put her at risk for declining health:

Alison: *“So when I like somebody, I’ll give them almost everything I have, you know, but some people are there to take everything you have, you know what I mean... Yeah. That’s why I don’t go to church, because when I go to church, they’re like, give everything you have, be real nice to people. No! I don’t go to church anymore. I’ve got to take care of myself, you know.” (p 40)*

### **Development of symbolic gestures.**

Most consumers seemed to utilize various symbolic gestures, either verbally or non-verbally, to communicate their firm intentions to incorporate medications into their lives. Although it is unknown whether their intentions will indeed become a permanent part of their lives, the use of language and gestures that indicate a commitment to medications was revealed in the data. This could be seen as a development of self-awareness through discovery and change, although this may have been a more intuitive action for many than what is learned in the traditional sense.

From the time that he showed his father the pill on his tongue to the time of his participation in this study, Sean has regularly stayed on his medication. He is able to verbalize his intent to stick to medication, despite the side effects. His regular medication use assures his pledge was indicative of his life-changing decision:

Sean: *“Well, I’m pretty much to committed to the medication stuff. I’ve kind of like been through the cycle of jail, hospitals, and doing it like two or three times.” (p 30)*

Sean explained that he keeps a symbol in his wallet to help remind him of his incredible change relative to where he was before:

Sean: *“Yeah and I, well, there’s one thing I do. I have like an I.D. that I keep with me, like when I got out of jail, they gave me an I.D. a temporary I.D. so I could establish my regular I.D. so I could get a social security card and stuff. So I keep this jail I.D. in my wallet, you know. I should have thrown it away, but I mean, I keep it so I could kind of like remind myself where I’ve been. Um, I keep it in my wallet, I don’t look at it that much, but I know it’s there.” (p 14-15)*

Another sign of assimilating medications into daily life was the ability, as in Dan’s case, to give simulated advice to consumers struggling with medication non-adherence:

Dan: *“It would probably bring hope. Probably if they stay on it, they’d be able to see improvements with themselves...It’s in their best interest probably. But I mean it changes from person to person too I think. I mean some people might be misdiagnosed or they might not....they might be treated in a way, like psychology maybe instead of with medication, but if everybody’s kind of saying, you know, it’s probably a good idea to take medication, then I’d say if you look at your life now and it’s not that great, probably it could be better if you take the medication.” (2/p 29)*

### **Permeation of Fear and Insecurity around Medications**

Another theme that consumers brought to bear concerning medication adherence was the incessant permeation of fear and insecurity. Through each of their illness courses, consumers explained in unique ways how the emotions of fear and insecurity were substantial elements of their beginning and continued experiences with psychiatric medications. This sense of being on the edge of uncertainty contributed to their hopes and expectations concerning medications. It was as if they never could be too comfortable while taking medication, as doubt flooded their thinking.

Consumers admitted to these emotions to varying degrees and in ways characteristic of the people they are, their unique symptom profile, and the environment in which they live. For at least one consumer, Dan, fear could be seen as a primary driving force in his decision to take medication. For other consumers, these intense emotions were demonstrated in other ways.

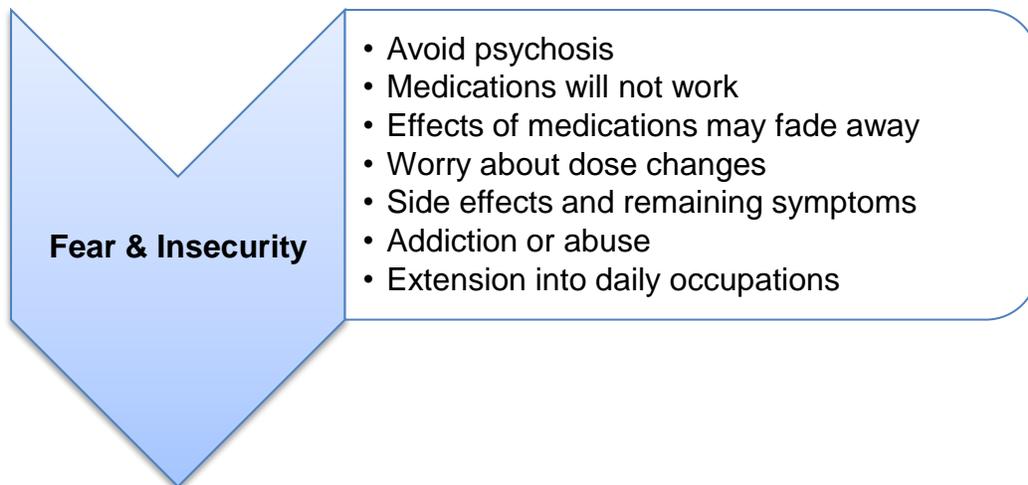


Figure 6: Fear and Insecurity. This figure illustrates features of fear and insecurity as distinctively experienced by consumers.

Facets of this theme (*Figure 6, above*) are discussed according to idiosyncratic ways that consumers experienced these emotions: a) out of a desire to avoid intense psychosis, b) out of concern that medication will not work or its effects will fade away, c) in the face of potential medication dose adjustments, d) as a result of negative side effects and remaining symptoms, e) out of uneasiness around addiction or abuse, and f) as an infiltrating extension into daily occupations.

**Angst arising from a need to avoid intense psychosis.**

Two consumers, Dan and Alison, expressed their intent to stay on medications for fear of relapsing psychosis. In some cases, fear was observed to be a primary driver of adherence decisions, as in Dan’s case, to avoid terrifying psychosis:

Dan: *“I think I’ve always been pretty compliant. I know that I was always scared of not taking my medication because I remembered what it was like before, like when I got sick, so I didn’t want to go back, yeah.” (1/p 11)*

His experience of psychosis caused misery:

Dan: *“I remember being very depressed and like I’d go out into public and see everyone and think that, like be self-conscious to the point of just, uh yeah (chuckles) like just you know thinking the world revolved around me...the intensity of it was scary...I’d be paying attention to how everybody was, like everybody’s behavior was and like how if I blinked my eyes, maybe somebody would do this...like a slight move by me and it has these big waves all over the place...so it was pretty terrifying.” (1/p 12)*

As indicated within her ideas about why she takes medication, Alison also fears the experience of another breakdown. Although she admits to contemplating non-adherence, the thought of revisiting intense symptoms is reason enough to take them:

Alison: *“No [I did not ever decide to go off my antipsychotic medication], because I know I’d have another nervous breakdown, I don’t feel like going through that again...Well yeah [I think about it], but I mean, I don’t do it. I wouldn’t do it without a doctor’s permission.” (p 56-57)*

#### **Worry over whether medications will work or its effects will fade away.**

Dan was the primary consumer who worried over whether medications would continue to work for him. Dan experienced the overwhelming anxiety of medications as his “last chance.” Although taking the new medication Clozaril, thought to be a kind of wonder drug, was difficult to endure initially, he held out hope that what started worse would eventually become better:

Dan: *“I just figured it was my last chance. So. I felt like it was my last chance, yup. If Clozaril doesn’t work, then. And I just, I like. Okay, so I’d get up every morning and be terrified. I’d be hallucinating and not knowing what was going on around me. And everything that I did was unreal and terrifying. I mean the symptoms were horrible.” (1/p 17)*

*“I think I can be stabilized by medications and I hope, I mean, I don’t want Clozaril to wear off, you know, like maybe Zyprexa did or something.” (2/p 26)*

#### **Uneasiness in consideration of potential medication dose adjustments.**

For Rebecca and Alison, the thought of changing their medication dose, even with a doctor’s help, brings about fears of what could be life consequences for them. Rebecca

holds on to hope, fearing a reduction in her dosage of current medication will interrupt her newfound equilibrium:

Rebecca: *“But I know that sometimes you can have lapses. So I’m not you know I have my fingers crossed and just you know that’s why I don’t want to change the medicine because it’s working.” (p 41)*

When her doctor proposed trying a lower dose given her emotional stability, she decided to postpone the reduction:

Rebecca: *“Yeah, but I don’t want to. I just want to keep it the same for a little [while]. Because I feel like I’m getting kind of a good start right now and so I’d rather just keep it the same for a little while and then look into lessening it later...I just feel pretty balanced.” (p 15)*

Alison also feared adjustment of her current medication dosage in either direction.

On the one hand, she feels she does not have a high enough dose to manage her symptoms. But on the other, she fears the consequences that higher doses could bring:

Alison: *“I don’t think I’m taking enough medication too. Sometimes I think I’m not taking enough...I don’t want to have another nervous breakdown, but if I take more, I’m like a zombie, so I don’t want that either, you know.” (p 37)*

### **Fear as a result of negative side effects and remaining symptoms.**

Although Sean did not express many fearful emotions during his interview, he was extremely uncomfortable with the weight gain he is living with as a result of taking his antipsychotic medication. He was so bothered by this side effect that he worked with his doctor to lower his dose of medication in hopes of losing weight:

Sean: *“Well I was just taking Geodon. I initially was taking 80 milligrams, then I was taking 60 milligrams, then I was taking 40 milligrams, so now I’m taking like 20 milligrams once... Well I mean I’ve been taking less and less. I was hoping that maybe if I took less, I would lose some weight, but it hasn’t happened.” (p 17)*

### **Uneasiness around addiction or abuse.**

Alison and Rebecca brought forth their insecurities about becoming addicted to medications. Alison expressed fear of addiction to medication and “high fructose corn syrup.” Her idea of being addicted to corn syrup is a reflection on her perceived weakness toward eating excess carbohydrates and sweets. But she also views psychiatric medications as an addiction:

*Alison: “They’re just calling it corn syrup, and there’s some interesting ramifications, because I’m hooked on that stuff, that’s part of my addiction. I’ve gotten rid of all my addictions except for high fructose corn syrup and psychiatric medication...Well, it’s like a sanctioned addiction.” (p 14-15)*

She responded to her fear of addiction by giving away the medications she felt tempted by:

*Alison: “I just gave my friend, Brenda, a bottle of, oh I forgot about that, Ativan. My doctor gave me Ativan, I had sixty pills but I thought that was too many to carry around. So I gave it to Brenda to hold for me...but I haven’t taken it, because I don’t want to get addicted to it. Because that’s one more thing that’s going to slow me down. Because I thought I could just take that whole bottle, just like that, you know...Well they’re so little, you could just take it probably one set, you know, there’s sixty pills are like a teaspoon, they’re so little. You know, I think they’re dangerous.” (p 49-50)*

Rebecca also alludes to her discomfort with taking too many medications for fear of becoming overly-reliant on them:

*Rebecca: “I think you should only take it if you have to. You know, you don’t want to get addicted to medicine or any type of drugs.” (p 24)*

### **Fear as an infiltrating extension into daily occupations.**

Primarily for Dan, his fear about medications seemed to creep into the occupations of daily life that some may consider non-health focused. But for Dan, life activities were another source of apprehension. Work and socialization with others, as recommended by his doctor, were seen by Dan as necessary aspects of his treatment, close if not equal to his use of medication:

Dan: *“Like every day I made sure that I got up on time, went to intensive day treatment, uh, was around people and that’s, Clozaril helped me with that. I think that would be a negative symptom if I was withdrawing. But actually I did that with Zyprexa, but I was so terrified that I wouldn’t get better that I just had to follow what the doctor said and I like quoted to the letter of the word (chuckle). Or, the word of the letter.” (1/p 17)*

He showed up to work each day no matter how he was feeling. He explains his fear about not working:

Dan: *“I wasn’t doing very well [when I was working] then either...I figured I needed to do it or else I’d just get lost or something...I was afraid of not going to work at all. I was afraid of not going to work because I thought I would have horrible, horrible symptoms...like something horrible would happen to me if I didn’t go to work, and plus I was horrified that if I didn’t do a good job, then that would be another problem.” (2/p 5)*

*“I was always afraid, sure. But I figured it was something I needed to do and I mean I was kind of thinking like I’m thirty-three, I just can’t, I just can’t accept my illness. I mean, I can’t accept it for the rest of my life. I’m going to have these things, these problems happening and so you know my doctors all said that that would be, the you know those things are important, going out, having a schedule, you know those things and I was terrified [CHUCKLE]. If I didn’t have some structure that I’d never get out get better or stuff like that.” (p 6)*

The sense of dread has not left him even in periods of relative stability:

Dan: *“And I still am [afraid]. Sure, I’m afraid that if I just do the slightest thing wrong, like there won’t be any way back.” (2/p 6)*

### **Consumer Experiences of Social Support by Families**

Consumer participants in this study had much to impart regarding perspectives and experiences with social support by their families. As an added social support component that emerged in this study, experiences with healthcare providers will also be reported here. The consumers’ social environment produced several topics of discussion across cases, including: a) desire for autonomy, b) boundaries of family involvement with health, and c) influential but disappointing experiences with healthcare providers. Their experiences, though distinctive and unique, shared these common threads.

### **Desire for Autonomy**

Time and again, consumers communicated in their own ways how important it is to have autonomy. Each young adult consumer in this study desired to be an agent of his or her own life and to accomplish tasks that are typical of this phase of life. Consumers brought forth their notions of what it means to be independent through discussion about concepts including: a) separation from parents, b) aspirations to progress in life, and c) grief over loss of independence in the face of illness.

#### **Separation from parents.**

Two consumers, Dan and Rebecca, were the most verbal about the desire to separate from their parents and live life more independently. Sean and Alison did not express the same notions of wanting to separate from their original families in their current life situation. Dan leaned on his mother for a long while before experiencing the desire to do more on his own:

Dan: *“Living in the city was a big change and it was a big stress and then that’s when I like wanted to move away from my mother, become more independent...”* (2/p 9)

He attempts to explain his complex feelings about detaching from his mother:

Dan: *“Um, I think we look at it differently and I think we’re just like there’s something that we each like I feel like....yeah, it’s I don’t like.....it’s like I don’t know, it’s kind of like there’s something....some difference in what we think is going on or something like that or difference in interpreting what each other needs, but it’s kind of like she might think I need something, but I actually don’t really need that or something, but instead of addressing it, it might be kind of passive/aggressive or something where you know, like instead of saying Dan, do you want to blah, blah, blah? You know, I don’t know....it’s like parent/kid.”* (2/11-12)

Rebecca experienced her mother’s choice of doctors as a barrier to her ability to independently manage her treatment visits:

Rebecca: *“My mom was forcing...kind of forcing this particular doctor onto me...she felt that he was, you know, he was obligated to, you know they had a close relationship.”* (p 27-28)

She preferred to be the agent of her health:

Rebecca: *“I mean sometimes I can see the necessity for family in a group, but I do like having my own private consultations...not too much interference.”* (p 48)

Alison’s story is unique as she had already separated from her father and began a new life with her husband. Alison’s young adult life now includes her new husband, and the prospect of potential parenthood:

Alison: *“[My relationship with my husband], it’s not that meaningful. I mean if we had a kid, it might be more meaningful, but we don’t so...but it’s a lot of work and I can’t barely take care of my own self, so I don’t think it will be really too fair you know...I’m going to be thirty-five...That’s like geriatric moms. I don’t want to do that you know. I don’t have too much time you know?”* (p 22)

#### **Aspirations to progress in life.**

Independence tended to have a variety of meanings for consumers. Having the freedom to persevere and reach for their dreams was a tangible value. Their intentions to live life meaningfully and set goals for themselves were evident across cases. Dan explains his enjoyment of creative writing and its link with his personal desire to continually grow:

Dan: *“Actually, I did [share my writings] at the [treatment location]. I’ve gotten a couple of publications actually. Poetry and another short story...well, I always wanted more. I wasn’t content with just (laugh). I don’t know why, but...I didn’t think I could make any money out of [writing] but I enjoy doing it.”* (1/p 5)

Alison has been challenged by weight gain due to her medications, and would like to eventually inspire others through writing a book:

Alison: *“Well, I’d like to um, lose weight and then have some sort of, you know maybe some sort of you know like self-help book kind of thing...you shouldn’t give up because you never know what can help you next, what’s going to inspire you next, you know.”* (p 48)

Sean is focused on developing skills needed for work and his household:

*Sean: "Well I'm still getting adjusted, I've been there three weeks, I watch a little television, I'm trying....I'm studying, I'm going to take a test in July to see if I can join the plumber's union, so I've been studying for this test... I've been cooking a little bit, you know, usually I use the microwave, but now I've been expanding the pots and pans and stuff like that. Yeah, so I can make small things like spaghetti or chicken maybe, I made some home fries this morning." (p 25-26)*

He aspires to work and have relationships:

*Sean: "Yeah well I would hope that I could function a little better than what I am now. Be able to hold a job, you know, have relationships, you know, those types of things." (p 23)*

Rebecca finds relationships meaningful, as it fits closely with her future desires in her life:

*Rebecca: "I think friendships are valuable, very valuable and good family relationships are very important too. I mean I'd like to get married and have children so that's important." (p 9)*

*"Just having a normal life, getting married, having children, living in a house, having a car, taking them to school, you know, those types of things." (p 11)*

She explains her desire for independence and its link with her ability to drive and manage her health:

*Rebecca: "I think I'm not as independent and I want to become more independent. I think that's a symptom and so I'm more in control of what I do and you know, I know that I want to be able to drive again....And I also would lose weight that way because I feel like I'm always sitting around waiting for people [chuckling] and their schedules...I mean, I do better [with managing my weight] when I can drive and stuff like that..." (p 43-44)*

### **Grief over loss of independence in the face of illness.**

Consumers in this study used language that indicated a grieving process for the independence they once enjoyed. Dan reflected on the difference between his past

capabilities to care for himself as compared with now, after his particularly difficult relapse two years ago:

Dan: *“Like I used to be able to support myself completely. And you know keep up with things pretty well on my own...I had a hard time over the past couple of years. So, I’d be socializing with people in a kind of work environment. I’d volunteer for a non-profit and there would be like happy hours or whatever...But for the past 2 years, I haven’t really socialized much.” (1/p 4).*

He has never forgotten the first blow of being diagnosed with illness, illustrated by its impact on his self-concept and self-efficacy:

Dan: *“So in a matter of about like six months or eight months or so, my life went from like being an A average to F leap who you know had a whole bunch of friends to okay. Well I have a mental illness and I’m going to have it for the rest of my life and I dropped out of high school, blah blah blah blah.” (2/ p 16)*

Sean has come to the realization that he and others who struggle with mental illness have had to or will have to rely on other people in life due to the nature of schizophrenia:

Sean: *“Well the whole thing about it is that like mental illness is not like, it’s kind of different than something like other illnesses. Like the person who has mental illness, a lot of times he doesn’t know that something’s wrong with him. Like if somebody is people making observations about him that he can’t make by himself, you know.” (p 6)*

Sean goes on to explain his grief over loss of time in his life due to his struggle with illness, and his feeling of being stuck for so long:

Sean: *“Yeah well, yeah I mean I’ve lost a lot of time though. I mean I think about things that people accomplish in their lives and you know, I’ve lost so much time because I’ve been just kind of been stuck in the same place, I guess.” (p 15)*

Through tears, Alison grieves her necessity for medication. She tries to have a positive outlook on her future in spite of the difficult challenges:

Alison: *“I was 130 pounds at 22 you know? I got hooked on fructose corn syrup and psychiatric medication. It sucks! But despite all that, I’m not going to have a crappy life [CRYING]. I’m not going to have a crappy life...I mean even taking medication and*

*being fat, I'm going to show everybody that I'm going to have an okay life, having schizoaffective disorder. (p 47)*

### **Boundaries of Family Involvement with Health**

Not so distant from the preceding theme of autonomy, consumers explained how they experienced family involvement with their health condition. In distinctive ways, they discussed matters about their families in terms of: a) unsupportive involvement, b) responses to unsupportive involvement, c) supportive contributions, and d) projection and understanding of others' behaviors.

#### **Unsupportive involvement.**

Because young adult consumers in this study desired to rely primarily on themselves and their providers, some participants expressed their perception of families as demanding too much relative to relationships and involvement with treatment.

Relying less on his mother and more on himself was no easy task for Dan:

*Dan: "But it seemed like [my mother] still demanded things of me that were difficult, like meeting with her every week...whenever I got to feeling worried I'd call her first and basically I'd tell her all my worries...but I thought [my worries] were kind of run of the mill...they wouldn't be resolved by talking to my mother. Instead it would be the same dependence or whatever." (2/p 9)*

He explains his desire to handle his problems by depending on providers:

*Dan: "I didn't want to tell my mother what was going on. I wanted to solve the problem myself. Like I was having problems living with [my mother and stepfather] and I wanted to be able to handle it myself rather than like making my mother overprotective or have to make decisions for me or stuff like that. I wanted to deal with it in therapy...I was trying to kind of start my own life...it was very difficult because I felt like my mother, like I wasn't able to have my own life and still doing what my mother expected to kind of have a family all there. And she mentioned a couple of times that I wasn't talking, but there were, I felt uncomfortable around her husband..." (2/p 4)*

Rebecca does not seem to endorse a close relationship with her brother and sister, but she described the complexity of these feelings in relation to her mother's unsolicited disclosure of her illness:

Rebecca: *"I mean it's kind of frustrating that my mom, this all comes from my mom. It's not something that I've talked to them about myself and so I wish it were something that I had talked to my friends with about myself that I can't talk to my siblings about, but instead it's my mom that's doing the talking you know."* (p 48)

Sean and Rebecca commented about their parents' judgment over their weight gain. For Rebecca, this was very bothersome:

Rebecca: *"Sometimes they talk about my weight and my weight gain and you know it's kind of like, it's not that they're out of concern, it's out of like duty you know? You know, that like makes me feel like I'm ugly you know what I mean?"* (p 49)

She went on to explain her feelings about the negative interaction on her sense of self:

Rebecca: *"Guilty...so that doesn't make me, it doesn't inspire me to want to lose weight."*

Sean's mother, who notably grew up with a mother with schizophrenia, expressed an opposing viewpoint about medication because of her worry about her son's weight gain. Sean sided with his mother's concern over the weight gain, not seeming to take it as personally. He thinks his mother's opinion probably contributed to his ideas about backing up on his antipsychotic dose:

Sean: *"Well she was like well maybe you should consider not taking as much medication as you do because of weight gain and side effects and you know, I mean she was concerned about my health, physical health as it relates to the medication I was taking because I would always gain a bunch of weight and that's not good."* (p 21)

Another way that Rebecca experienced unsupportive relationships was in the manner her parents reacted to her medication non-adherence:

Rebecca: *“Like I was getting worse. I mean I was getting worse. So when somebody’s getting worse on medication, you have to really acknowledge that and not just listen to the doctor, but say okay well maybe we need a second opinion.”* (p 37)

Dan endured opposing opinions of his parents about taking medication when he was first diagnosed. His father’s judgment was an unsupportive presence at a difficult time in his life:

Dan: *“Well, I didn’t really think my father was like thinking so realistically about things. His mother’s sisters had schizophrenia and both lived in mental hospitals for a long time, and basically I didn’t want to do that. His brother committed suicide and I didn’t want to commit suicide.”* (2/p 17)

*“Oh, boy, it’s always been a big mess, but or at least it seems that way to me, nobody knows anything for sure, and my dad didn’t really accept that I had an illness. He thought it was kind of like a decision I made to identify myself as being mentally ill...[he thought] I could deal with the problems I had in a way that I wouldn’t need to deal with medications, taking medications.”* (2/ p 15)

### **Responses to unsupportive involvement.**

Consumers’ reactions to their family’s involvement were also reflected by participants in this study. Dan seemed to indicate that the motherly role is symbolic of dependence, whereas the brotherly role feels freer. He has recently come to rely on long-distance phone calls with his brother for advice:

Dan: *“Practical tips from [my mother] feel like she’s taking care of me...but I know that I can take care of myself you know wake up and do the things I need to do and I notice the less she watches over what I do, the more empowered I feel to do it myself, you know?...My brother doesn’t really ask ‘so, Dan, have you cleaned your room?’ or ‘Dan, are you doing this, that and the other?’”* (2/p 11)

Rebecca reacted to her mother’s intrusiveness by expressing her boundaries, including her desire to utilize providers as her main source of support for illness management:

Rebecca: *“I just let her know that she’s not a doctor and that I need to talk with the doctor if the medicine isn’t working...She’s tried to step into that role a couple of times, but I just go directly to the doctor and that’s why I’ve kind of had to kind of cut her out*

*from some of my experiences with the doctor. I mean, she's been very you know, 'who's your doctor?' She really wants to know, you know, who I'm seeing and this that and the other. But you know this is a relationship that's directly between me and the doctor and it's my call. I know that she's curious, but she has to worry about her own health too."* (p 17)

She succeeded in excluding her mother from choosing her doctors or participating in her treatment:

*Rebecca: "[Now] she knows the name, but she's not meeting with the doctor like she was with some of the other doctors. [It was bothersome] because it's like she's trying to answer questions for me when she's not me. So it causes confusion...It's my private meeting."* (p 18)

Some consumers, like Rebecca and Alison, desire particular boundaries around helping them with their medications:

*Rebecca: "It's a medicine that works for me. I don't mind taking it. I don't mind her asking me if I took it. I have a problem that she tries to play doctor, you know. That she tries to become the doctor and make sure that I'm taking it. When I really need to see the doctor as opposed to you know, having her try to become the doctor and taking it. I have a problem with that, but other than that I don't mind her asking."* (p 17)

She doesn't believe that it is necessary for her parents to pressure her about her medication anymore:

*Rebecca: "No, I think it's going very well right now. So you know adding pressure to take it, take it doesn't really make any sense, because I'm taking it!"* (p 37)

Alison, half jokingly, keeps her "nosey" husband at a distance when it comes to her illness:

*Alison: "Yeah, but I don't want [my husband] to get sucked into it, you know, so. It's a part of my life but it's not totally everything you know...Um, he's nosey...I think he's trying to say he's mental too. He wants in on the band wagon too; you know....I have no idea [why]. I wouldn't want to...I've been on it for like twenty years and I prefer not to."* (p 6)

*"Sometimes [my husband] reminds me [to take my medications]. I mean he's not always there you know...Yeah, so it's hard. I don't want him to have that role either you know. It's not really that great."* (p 50)

She also lightheartedly lets her father know his boundaries on the infrequent occasion of his reminding her to take medication:

Alison: *“Well no, he’s talking like, have you taken your medicine? And then I just say, go to hell or something [LAUGH].”* (p 51)

### **Supportive contributions.**

Despite the difficulties of the family relationships around medication and illness management, each consumer had positive experiences with their family support as well.

Alison’s father, who also lived with schizophrenia, kept her out of the hospital by setting up a makeshift mental health program at home. Part of his design actually included his suggestion for Alison to take a pottery class, to mimic the occupational therapy sessions he had while hospitalized:

Alison: *“No, I never went to the hospital. My dad took me into, he had an apartment at the time and he just kind of let me do what I wanted to, I took a pottery class and kind of just hung out, you know, for the summer and didn’t do too much.. He took a pottery class that was...I hate pottery! I hate making pottery, but at least I learned you know that I hate making pottery...I like pottery to buy it, but you know, no. Oh no...I’ll never touch clay again!”* (p 20-21)

Alison: *“I mean he helps a lot, he’ll tell you that he’s helped me a lot when I lived there, but now I don’t live there anymore.”* (p 45)

Although Dan has had some negative feelings about making choices in his healthcare, he expressed that his mother supported him in making his own decisions:

Dan: *“Right, it’s always been, I mean, it was always my decision what I did. Like when I was 14, I think I asked to see a psychologist before I had my first breakdown, but that didn’t seem to work out. And then like I went to the mental hospital and I started, I decided to go to the mental hospital, you know. Basically my mother and father said, ‘well, it has to be your decision’ and then I decided to go again to the hospital when I was 17 and then this time, like my care has been basically left up to me but I guess, you know I think that like people supported my decisions, except for my father.”* (2/p 19)

He also looks back on the early days of his illness when his mother used her research talent to find information, in addition to spending time listening to him:

Dan: *“In high school when I first dropped out, I think [my mother] probably; well she spoke to me every day without a doubt. She watched over, you know, she kept up to date on the research and stuff like that and gave me advice and told me what the doctors were saying...It was good. I guess I’d talk to her very frequently, often very late at night and one thing she did that probably most people wouldn’t do, is that she would just listen to me. Like she’d, instead of saying ‘no Dan, you’re wrong’ or blah blah blah, you know ‘you’re just making this up in your head.’ She’d just listen and say ‘hmmm, okay, okay...I never really thought of it that way.’” (2/p 8)*

Sean made a point to compliment his father for seeing him for who he really is, in spite of his mental illness:

Sean: *“Well, he treated me the way he always treated me. He didn’t, you know, I guess he saw the same person. He didn’t change his behavior toward me in any way.” (P160)*

His uncle, who was in the healthcare field, also played a role in supporting Sean when he was first diagnosed. Of note, his uncle also was in a position to offer support based on his own experience with Sean’s grandmother’s struggle with schizophrenia.

Sean: *“They told [my uncle] what my diagnosis was and my uncle was very supportive and he was telling me that, you know, I could still have a life that was productive provided I followed up with treatment as far as like medication and seeing a therapist and things like that.” (P108).*

Sean is also grateful for his family’s belief in his potential:

Sean: *I don’t know, I guess that I would thank [my family] for supporting me in the time of crisis and you know I would thank them for continuing to have expectations of me... I mean, basically, to have the same responsibilities that most people do and not just to function...” (p 31)*

Foremost in his interview, Sean expresses that he owes his current independence to his family:

Sean: *“Well it depends on how you define live on your own, I mean, I’m more in my home technically, but I get a lot of support from my family, like my father, my father bought me furniture, paid my first months’ rent, security deposit, you know, so my father has been kind of like the driving force as far as me being able to live independently. So, I don’t know where I would be if I didn’t have my father supporting me...I manage to pay my bills, but you know he does help as far as like food and clothes and taking me to places, so yeah.” (p 4)*

Rebecca's parents have played a role in observing whether her current medication routine seems effective, which is welcomed:

Rebecca: "[They say] 'oh, this medicine really seems to work now.'" (p 15)

She went on to explain what she would ideally like in her relationship with her family:

Rebecca: "I mean just encouraging that they see improvement with me. That's helpful."

(p 35)

*"Well, I mean it has to be truthful first, but you know just through friends and family and you know I mean just more interest I guess too. Just like, you know, maybe it's not so much that, I mean. Like when I have a party they'd come or you know just that type of thing. Like doing more together and showing that you know that I'm a valued person."*  
(p 35-36)

*"I don't want people to go out of their way or like be, you know not truthful but that's just one way that shows positive."* (p 36)

Sometimes environmental social supports took on a more imperceptible role, contributing to consumers' awareness without them knowing it. Dan utilized a strategy of visualizing family and friends' reactions to his symptoms as a reality test. He would also use the backdrop of a public environment, such as a store or restaurant, as a check of his reality. Dan reflected on a time when he was enjoying his symptoms and incorporated this vision:

Dan: "I guess it's kind of like when you get to a certain point and you look back and think. You kind of see yourself in the perspective like the future or like the past and when I saw myself, 'okay, so like what does this mean in like, like if I'm around my friends this wouldn't, this wouldn't make any sense' (chuckles). It was fine if I was alone in my own world...what would my friends say? But when I tried to go to the store or tried to have dinner with my parents or something it would be just the opposite. I'd think, 'well, okay, this isn't very good.'" (1/p 18)

He also recalls an occasion where he forgot to take his medication one night, the outcome being symptoms of mania the next day. He noticed he was more productive

than he usually was. Again, he utilized his social supports in an invisible fashion, evaluating whether other people noticed the change. He observed that other people did not say anything to him nor seem to notice anything out of the ordinary. What he did detect is that people seemed to enjoy being in his company on that particular day, which was also overwhelming in its own way.

Dan: *“I felt much better [when I forgot my medications] but no one said anything. No one said, ‘oh, Dan, are you feeling okay?’ Or ‘are you alright?’ In fact they seemed to enjoy being around me more and stuff like that. But I know that I can’t deal with that too much because, like it definitely overloads me. Even if it’s just all in my head.” (1/p 25)*

In fact, Dan’s brother may not be aware of the role that he plays in Dan’s life, now that he is trying to involve his mother less:

Dan: *“[My brother] actually helped me a lot also. My mother, hasn’t worked out well in the past ...because like I haven’t been able to deal with my own feelings or my own life, you know, like taking care of myself...But my brother doesn’t make a judgment one way or another. Just he might offer like logical things or you know help me make decisions one way or another...he helps me with practical things like he might say ‘well, here’s an appointment book’ or he might say, he might be a good reality checker like if I say you know is this going on? He’ll say, ‘no, that’s not going on.’ He won’t laugh...” (2/p 11)*

### **Projection and understanding of others’ behaviors.**

Most consumers illustrated that they were sometimes able to put themselves in their family’s shoes. Rebecca was able to think about her mother’s feelings and rationale for reacting in the ways that she did regarding medication non-adherence:

Rebecca: *“I mean I think she was doing the best she could, but you know. And I still think I should have had a second opinion and I eventually did. And it was not the right medicine for me.” (p 39)*

Dan not only thought about his mothers’ feelings, but seemed to protect her at times from what he considered to be burdensome health problems:

Dan: *“I thought that already the stresses; the household stresses were very intense. My mother, I thought, might be having marriage problems. I felt uncomfortable. I felt like I*

*was getting between them just like I got between my mother and my father. I thought that if I started talking to her about, you know, I'm talking to these people that aren't there, and blah blah blah, that she'd be just, that would, she'd have a nervous breakdown." (2/p 7)*

When Sean was asked to reflect on his father's decision to put him out of the house, resulting in his homelessness, he was able to envision how his father must have felt:

*Sean: "Well, I would imagine that it was hard to deal with somebody who's, I imagine it's hard to deal with somebody who's ill. So sometimes I might have been just too much to take...I mean you love your family, you know, they're the closest people you have. Sometimes you get upset with them, but ultimately they're related to you." (P310-P312).*

### **Influential but Disappointing Experiences with Healthcare Providers**

Acquiring a healthcare provider standpoint was not a goal of this study, but consumers explained how they bore close witness to providers' words and actions in the course of their medication monitoring and other treatment. This major topic could not be neglected. Experiences with providers emerged according to topics that include: a) unsupportive relationships, b) supportive relationships, and c) ideal wishes for support by providers.

#### **Unsupportive relationships.**

Some consumers reported on their physicians' unwillingness to change their medications, despite negative effects:

*Rebecca: "He seemed kind of lazy about it, about trying to change it. He might not have been very familiar with other medications, yeah." (p 34)*

*Rebecca: "I just don't think he was that qualified. I mean, I don't know, I guess he just didn't equate you know, take [my side effects] into consideration. That wasn't at the top of his list or what have you. And I didn't think he knew enough about other medications." (p 40)*

*Dan: "Oh, so I did see [the psychiatrist] actually eventually. But he never changed my medication even after I was telling him that I was having severely, uh, psychotic*

*symptoms...I guess sometimes it makes me really angry like, I mean like patients with mental illness might not have much of a case to say, 'okay, you've made me unable to work, unable to have social, uh, social relationships and you know my life has been turned upside down' but you know that's just the way it is." (1/p 22)*

Dan: *"No, I don't think I had the choice to say to my doctor, 'okay, this pill is not working for me, I'm having horrible symptoms. Please change it.' He didn't. He wouldn't change my medication." (1/p 23)*

Alison and Sean tried to consult their doctors about helping them with the issue of weight gain with an unsatisfactory response:

Alison: *"Yeah I complained about [weight gain] every time, but she didn't seem to really care...she didn't take me off of it, she didn't give me any helpful hints. She didn't do anything." (p 47)*

Sean: *"Why I talk to my doctor about it and he kind a gave like the obvious answer that you got to burn more calories than you're taking in and everybody knows that [LAUGH]..." (p 28)*

Expressing feelings about medications to doctors sometimes brought unsatisfactory responses, including dishonesty on the part of psychiatrists. One such experience was when a psychiatrist was perceived to withhold information about side effects of Dan's medication. He was not willing to admit right away that Clozaril did indeed cause joint pain for some people. Instead, Dan recalls that the doctor waited a year before he would confess. Dan described his response to the doctor's non-divulgence of information:

Dan: *"I didn't really have a choice, I figured okay well I could stop taking medication, but that might be even worse, and I started seeing a psychiatrist and told him I was having these side effects from the medication and he'd tell me, no that's not...this medication doesn't do that, but I mean I don't know how obvious it could be...I looked it up on the computer and it said it could cause those things." (2/p 2)*

He felt he could not challenge his doctor on the issue:

Dan: *"I had to believe him, I don't know...I mean I can't prescribe myself medications, so I have to say just be honest about what things are, what's happening to me..." (2/p 3)*

This contributed negatively to Dan's self-concept as he reflected on the possibility of just being a "number" in the doctor's eye:

Dan: *"I guess sometimes it makes me feel uncomfortable like, I feel sometimes like they're testing me or that I'm...that I fit into a definition that I or a personality type that I don't belong in or that my case is a routine case and so it's easier to kind of put up the wall and say, treat me ways that I don't like, you know?" (2/p 23)*

He was able to reflect on the psychiatrist's potential rationale for dishonesty about side effects of Clozaril:

Dan: *"Well, I guess I'd imagine that a lot of patients who have mental illness aren't very honest or as direct, uh, as me, but there might be some things like doctors just have to test out these things to make sure that the patient is telling the truth. Like say if I ask him, like I asked my doctor as soon as I started having trouble with my joint pain whether it could be caused by Clozaril, and he said 'nope, I don't know anything about that.' And then recently [a year later] he said 'yeah, sometimes it does cause that.'" (1/p 24)*

Two consumers, Alison and Sean, had experiences where their doctors mistook what was reported as a symptom instead of a real experience. Alison verbalized her difficulties about co-workers who were talking about her. Instead of believing Alison, the psychiatrist responded as if it was paranoia, which resulted in Alison's self-defensive response:

Alison: *"Oh yeah, because I used to have a psychiatrist that every time I said, 'oh, I hear people talking about me you know...She'd up my medication, so I got to be a zombie, you know. But it's not just me...I have proof yeah. I make sure I bring proof.'" (p 17)*

Sean illustrates a similar experience with his doctor when he first communicated his desire to take no more than one medication:

Sean: *"No, I mean I told him when I first met him that I don't like taking a lot of medications, I want to keep my medications to a minimum, I don't want to be taking a whole bunch of stuff and he was like, he thought that I was nervous or agitated and he was like, well maybe you should take this [Prozac]." (p 16)*

Dan spoke about the discrepancy in goals between himself and his providers, including his desire to do more than “maintain”:

Dan: *“It doesn’t seem like the goals that I have are the same as the goals that my [treatment location] has for me or whatever. I always want to get well, but it seems like it’s more of a maintenance type of thing. I might go to the case manager and just talk about really nothing or every once in awhile I might have practical questions about insurance or stuff like that. Psychiatrist, I’ve asked questions before and didn’t really get much of an answer, even though he’s supposed to be an expert and often uses ‘I don’t know’ or whatever, even though it seems like a question that he’d be able to answer.” (2/p 27)*

Dan also experienced a sense that he did not matter when visiting a past therapist:

Dan: *“I had insurance and she, like I believe that she dealt directly with insurance companies, but she had me during the session get up and call the insurance company to make sure I had insurance for the session. But I mean, I didn’t think that would be an appropriate thing to do at therapy. And another thing that she did was, I’d claimed something like, I think like, or I had claimed something or I’d say something like blah blah blah, I’m feeling really horrible, you know, I feel like a horrible person and blah blah blah. I felt like she didn’t trust me and she often said, ‘I don’t buy it...’ and it was really difficult another time, I think I broke down crying feeling like I was a bad person and it was just like looking at a wall or whatever.” (2/p 24)*

### **Supportive relationships.**

Although consumers’ positive experiences seemed few and far between, there were in fact a couple of encouraging moments for consumers. When one of his doctors agreed to change his medication to a newer generation antipsychotic, Dan was pleased with this. However, as this quote illustrates, he has struggled with confidence in his own abilities to manage his health care:

Dan: *“I thought it was great. I, yeah, I’ve really not been very assertive in my care, but I have always said that....or I always thought that maybe I just don’t know. Maybe that’s common with a lot of people that aren’t informed or maybe use drugs people don’t know much about.” (2/p 14)*

Notably, Alison’s current psychiatrist explicitly responded to her idea of potential future pregnancy by lowering her antipsychotic dose:

Alison: *“I was taking 40 mg [of Abilify] ...[Now] I’m taking 10...I told them I wanted to have a baby. I told my psychiatrist. And he said it was against his best judgment, but he was weaning me off of it... Well, he said there was no way I could go off of it and work. He said I could go off of it, but then they’d probably fire me.”*

However, although Alison was pleased with this reduction, one wonders if this provider’s reaction is more like “okay, I’ll do it...but you’ll be sorry!” She goes on to describe her positive relationship with her therapist:

Alison: *“Well, [the therapist] just kind of reminds me that, you know, [the medication] helps me feel better sometimes...we have a good time talking.” (p 51)*

Rebecca appreciated her inpatient stay at the research hospital the most, because she described it as “comprehensive.” She went on to explain why this setting turned out well for her:

Rebecca: *“The team approach and you know they caught that I was taking medications that I probably shouldn’t have been taking, so that was really important. Well, two medications actually... Yeah, it was a very thorough job.” (p 47)*

Sean also had the help of his psychiatrist to lower his antipsychotic dose in an effort to help him lose weight:

Sean: *Well I was just taking Geodon. I initially was taking 80 milligrams, then I was taking 60 milligrams, then I was taking 40 milligrams, so now I’m taking like 20 milligrams once... Well I mean I’ve been taking less and less. I was hoping that maybe if I took less, I would lose some weight, but it hasn’t happened.” (p 17)*

### **Ideal wishes for support by providers.**

When consumers were asked to reflect on the advice they would give to providers regarding medications, they explained:

Rebecca: *“Listen when the side effects are outweighing the usefulness of the medication. So the negative side effects, and try to get a second opinion and you know try to make sure that it makes sense to continue taking it as opposed to something else.” (p 40)*

Dan: *“I think it’s really, really important, I mean if someone’s going to be handling your medications, I’d expect, I’d hope that the psychiatrist would know the person pretty well before he’s you know changing the medication or like handling the medications or*

*whatever because I mean slight changes in medication can have big impacts. Plus, just to know someone with a mental illness might be really complicated...I would imagine it's pretty difficult to understand. So, I'd hope a patient and a doctor and a treatment team would, you know, in the best circumstances it would be long lasting..." (1/p 21)*

Dan goes on to discuss characteristics that are appreciated in healthcare providers:

*Dan: "Well, that's the thing, it's more of like a, it's a strange thing, it's more like a personality. It's almost like if I were, uh, like a friend sometimes or be someone who'd be like a mentor or someone who would be someone you look up to...who you think has knowledge or wisdom or experience or someone you trust. I don't really know how those things work or why they work, but probably both patients and doctors would be able to say, 'okay, this seems to be an okay, an okay treatment team'...and when you don't have it, it can be pretty, uh, not very good. Yeah it can lead to pretty bad things." (1/p 23)*

*"I'd say what you're doing now, with these interviews, that would probably be helpful yeah...like some of those similar questions. Like you know maybe show say, how other people have experienced things that are similar. Also, if you're open and up front about kind of these things, it might help...you know some real concerns that patients have, I mean, instead of trying to kind of test things or whatever. You know, just being direct, asking questions and stuff like that." (2/p 30)*

Alison also imparted advice to prescribers of medication:

*Alison: "I don't know, just like be careful what you prescribe to people you know. It's hard you know, because there's so many people that quit. [They shouldn't] make people into zombies you know." (p 57)*

Sean urges doctors to keep working on a medication that does not generate the no-win condition of emotional over physical health:

*Sean: "I don't know. I can only speak from experience, I'm not a doctor, but I guess the obvious would be to come up with something better. Something that doesn't.....something that effectively deals with symptoms and doesn't create new problems." (p 30)*

And, as he consistently stated during his interview, he wants providers to know that medication is only one part of treatment:

*Sean: "I guess the one thing I would say is to not put every hope on medication. I mean think of it as being a part of variety of methods, I guess." (p 31)*

## Consumer Views of Recovery

Consumers spoke about recovery throughout their interviews, whether or not they used language analogous with that found in the literature. They also completed two recovery-based surveys which explored personal views using the Mental Health Recovery Measure (MHRM) and general recovery attitudes with the Recovery Attitudes Questionnaire (RAQ-21). Narrative data, followed by surveys will be discussed in this section.

Their data on recovery in the context of taking medications and managing their mental illness was focused on consumers' experience of *liminality* as they brought into view their sense of being stuck in their world of illness. In addition, their ideas concerning societal stigma seemed to be part of their experience of being limited in their lives.

### **Between and between: Seized by life with mental illness**

Across cases, consumers shared experiences of being held back by their world of mental illness. It seemed they could only capture a brief vision of a "typical" adult existence before the reality of their arrested young life set in for them. Sean explains his outlook relative to his illness and use of medications:

*Sean: "I don't know. Like there's no cure for schizophrenia from what I understand, the medication just deals with some of the symptoms like hearing voices or delusions and things like that, but as far as like, my therapist tells me about negative symptoms like being withdrawn, not being able to communicate, things like that. You know, I still have that so I don't feel like I'm in as good of health as I would like to be. I'm just kind of like managing, I guess." (p 15)*

He expressed his view of himself along a perceived continuum in comparison with other consumers he knows:

Sean: *“Well I think I’m somewhere in the middle. I don’t consider myself low functioning, but I don’t function as high as someone like maybe (name of consumer who directs community program) I guess. You know like you look at her and you wouldn’t even think that she has an illness of any sort. I guess I’m in the middle somewhere.” (p 23)*

Although Sean does not hold solidly onto hope for a cure for schizophrenia as his previous quotes illustrate, he still imagines how wonderful it would be:

Sean: *“Well a cure would be great, that’d be very good. I mean there would still be challenges if I didn’t have an illness but a cure would be very good... Well I think I would like to be in better health than what I am now. I mean, you know, physically I would like to be in better health, but a cure would be very good, that would be very good.” (p 24-25)*

Sean looks at where he is in his life now, and is satisfied relative to where he was before.

However, he wants more in his life:

Sean: *“Ah, I’m in a better place than I was three years ago. I would hope that my life would improve. That there will be improvements continually, you know, I wouldn’t want to stay in one place....Ah, well I kind of like I’m isolated socially, you know, I mean I have friends, but I’m not like dating or anything like that and so I guess trying to expand my social circle, would be one thing.” (p 5)*

Sean also believes that recovery is not achieved alone, but that consumers have to take initiative with proper supports in place for them:

Sean: *“Well I mean recovery is not something that you do as an individual per se, you know, there’s times where you have to have some initiative, like in terms of taking your medicine and stuff, but you know, housing is important, it is very important, it’s probably more important than medication, I mean because like a lot of people with mental illness, they’re living in some type of institution.” (p 23-24)*

Sean: *“So and there’s a lot of things that you have to depend on others for like, you know, my family bought my furniture and bought me clothes and stuff like that. These are things I couldn’t do for myself, so I can’t take credit for it.” (p 24)*

Dan’s meaning of recovery has evolved through his illness. He articulates his experience of restricted possibilities:

Dan: *“Recovery, well recovery means a lot different now than it did before. I guess about the time that I was.....that I had my breakdown I was making a fairly good living. I*

*could have lived on my own, taken care of myself, enjoyed writing and music and I could have been more involved with ways of or things that would have....getting you know to be involved with things and have a group of friends and stuff like that, but now I guess, I'm not so....like I don't think I'm going to have a career that is necessarily like six figures and doing something great and important and all of that. I guess right now, I'm kind of on a maintenance type of thing, but I don't....I guess instead of like looking to the future and saying well you know I feel a lot less able than I did before this breakdown, like I feel like okay I can't do anything too exciting, I have to stay on a routine, take medications, get therapy weekly, you know, there aren't....I can't say you know go overseas for six months to do business and I can't like....I don't have a job right now where I'm working eight hours a day doing very stressful work right now. Maybe if I....I guess recovery for me means that I'm able to be independent, I guess. So hopefully at some point, I'll have a job that supports me that I have a future with or that I do have a professional life but it isn't as stressful and like, hopefully, I won't have symptoms even though usually I have like lingering things going on in the back of my head or something. I used to think that eventually I'd have that completely gone, but it just might be there forever. I don't really know. Recovery also to me means that I learned how to cope with symptoms like not pay attention to them or something like that.” (2/20)*

Furthermore, as his quote illustrates, Dan feels that he does not have an option to be adventurous in his life:

*Dan: “The one thing that does....is kind of difficult, is that I like, you know, I might not have as much of an ability to kind of move from one place to another. If I'm always in need of this level of care, you know, so I might not be able to move from [current location] to New York or [current location] to California or something like that....It's something I had hoped to have more control over now.” (2/23)*

He feels he is more realistic about his goals in life given his illness:

*Dan: “Well, it's more realistic I think. I mean most people realize probably a lot earlier that they're not going to rule the world or something (chuckles). Not rule the world but at least be like Gates or you know whatever.” (2/p 20)*

Dan wishes he could move forward with his goals in life:

*Dan: “Sure, yeah I don't want to be in this situation that I'm in now. Like I want to continually achieve things or work toward things.” (2/p 21)*

By far, Alison responded most boldly to the statement read about recovery. She and Sean share similar viewpoints of just hanging on:

Alison: *“Well that sounds nice...Yeah, it sounds like a doctor figured that one out [CHUCKLE]. It doesn't sound like a consumer decided on that one...I'm just holding on until something better comes along...Some sort of behavioral therapy where they can put in my brain and they'll tell me DING, do this now! You know, like I'll be a robot...Because then I wouldn't have to worry about like getting motivation to do things...” (p 54)*

Rebecca held out the most hope for a cure of schizophrenia, which was a unique notion in this study:

Rebecca: *“Well, I explain that an illness is not with you for life necessarily. You know, it's something you can heal from... So I just think that you know I express that with me and my particular situation it doesn't mean that I'm going to be schizophrenic forever or mentally ill forever. It just means that I have to work on it and try to heal. You know, and that's fortunate about my specific situation and not everybody's.” (p 45)*

### **Stigma.**

Rebecca explained that family and friends are vital for recovery, with the caveat that stigma should be replaced with knowledge:

Rebecca: *“I think that's right. And I do think that people are key like friends and family. Friends especially are key in helping for recovery, and I think sometimes people are scared of mental illness or they don't know how to react about it, but it helps to recover if people are, you know try to become knowledgeable and you know. And understand that every situation is different.” (p 42)*

Yet developing friendships has been difficult for her since the onset of her illness:

Rebecca: *“I'm fairly satisfied. I think I need to do a better job of keeping in touch with friends and making sure that, you know, it's a give and take in a relationship; in a friendship relationship. So, yeah I think that's something I need to focus more energy on. But, you know, I haven't had much money, it's just hard.” (p 6)*

Stigma and the media seemed to be an influence that also impacted consumers' lives with illness. Interestingly, Rebecca was impacted positively by advertisements on television regarding Abilify and its use for depression (as well as schizophrenia). This could have been incorporated into her eventual acceptance of her new medication:

Rebecca: *“And when I saw it advertised, it says that it’s for people who have depression and schizophrenia.”* (p 33)

Dan also talked about media influences, but in the way of stigma toward those with mental illness:

Dan: *“I mean most likely the things people know about people with mental illness is that it’s on the news and they have a guy that does a crime or something like that...so if people knew that mental illness wasn’t a bad thing...like people that are mentally ill are not morally incapable or whatever...lots of people have it and lots of people are successful that have it...”* (2/p 31)

Sean undeniably felt stigmatized while he was homeless and trying to survive:

Sean: *“Well the shelter on [location] that was the [name of shelter], that was closed because it was close to businesses and people don’t want to look at homeless people and so they moved, they have this shelter on [location], it’s way out of the way and you know, it’s kind of like hiding the people.”* (p 18)

Alison unabashedly explained her belief that society maintains unfair standards for individuals living with mental illness:

Alison: *“So I don’t really....I have some very....I really feel like I’m being forced to take medicine, I don’t like medicine, I wish I didn’t have to take it. [I feel forced by] society....I feel like as soon as anybody is a little different, they have to take medicine and they’re labeled...”* (p 11-12)

Although she expressed ambivalent thoughts about her emotions toward medication, societal pressures to take medication surfaced at various points in the interview. She wishes she would have not gone back on medication, tying her rationale to her sense of self:

Alison: *“No, I don’t know, somebody told me to [take the medication again]. I wish I wouldn’t have...Because it sucks... I wish I didn’t have to take something that makes a different person. [CRYING] ...It’s what everybody wants.”* (p 33)

Through tears, Alison also shared about her experiences with co-workers who talk behind her back because of her weight and her illness:

Alison: “*Uh huh, they talk about me behind my back, my coworkers do, they talk about me because I’m fat and they talk about me because I think differently, and I think that’s discrimination.*” (p 15)

### **Quantitative results.**

Each consumer completed two recovery-based measures, the Mental Health Recovery Measure (MHRM) [Young & Bullock, 2003] and the Recovery Attitudes Questionnaire (RAQ-21) [Steffen & Wishnick, 1999]. The purpose of using the MHRM was to explore personal views of recovery while the RAQ-21 provided insights into general recovery-based beliefs. For both instruments, the higher the total score, the more positive view of recovery. Both measures utilize 5-point Likert scales.

Descriptive statistical analyses were performed including total raw scores and percentages for both measures (*Table 4*). The mean score for the MHRM across consumers was 80.5 or 67%. The mean score for the RAQ-21 was 65 or 77%.

Consumer 2 (Rebecca) scored highest in both the MHRM and RAQ-21, indicating more positive self-reported recovery when compared with three other consumers. Consumers 1 and 3 (Dan and Sean) scored lowest on the MHRM, indicating less positive self-reported personal recovery beliefs. However, they both scored more closely to Rebecca in the RAQ-21 which indicates that Dan and Sean illustrated more positive general recovery attitudes when compared with their own personal recovery beliefs. Alison scored second highest in the MHRM and lowest in the RAQ-21, but her percentage scores were most consistent between both measures (72% & 74% respectively).

Table 4

## Survey Scores: Consumers

Participant	MHRM Raw Score (out of 120)	MHRM %	RAQ-21 Raw Score (out of 84)	RAQ-21 %
Consumer 1	71	59%	65	77%
Consumer 2	93	78%	67	80%
Consumer 3	72	60%	66	79%
Consumer 4	86	72%	62	74%

MHRM (Young & Bullock, 2003); RAQ-21 (Steffen & Wishnick, 1999)

Scores for six smaller conceptual domains for the MHRM were calculated (*Figure 7*) which included overcoming stuckness, self-empowerment, learning/self re-definition, basic functioning, overall well-being, and new potentials. Notably, there is only one item in the MHRM that addresses medication within the category of “basic functioning.” The RAQ-21 was reduced to two separate categories (*Figure 8*), including “recovery is possible and needs faith” and “recovery is difficult and differs among people.” No items in the RAQ-21 address medication.

Within the MHRM, the “overcoming stuckness” and “new potentials” subscales were most similar to the concept of being wedged between illness and freedom, as consumers indicated within their narratives. Analyzing these particular subscales made the most sense in terms of using the quantitative data to inform the qualitative, and vice versa. The concept of overcoming stuckness included items that dealt with working hard towards recovery, taking risks, asking for help, and the belief that things are improving in

life. The concept of new potentials included items that focused on quality of life, positive attitude, doing productive activities, and making progress toward personal goals.

As seen in Figure 7, consumers 1 and 3 (Dan and Sean) felt less able to overcome stuckness and move toward new potentials. Consumers 2 and 4 (Rebecca and Alison) felt more positive about overcoming stuckness and moving toward new potentials.

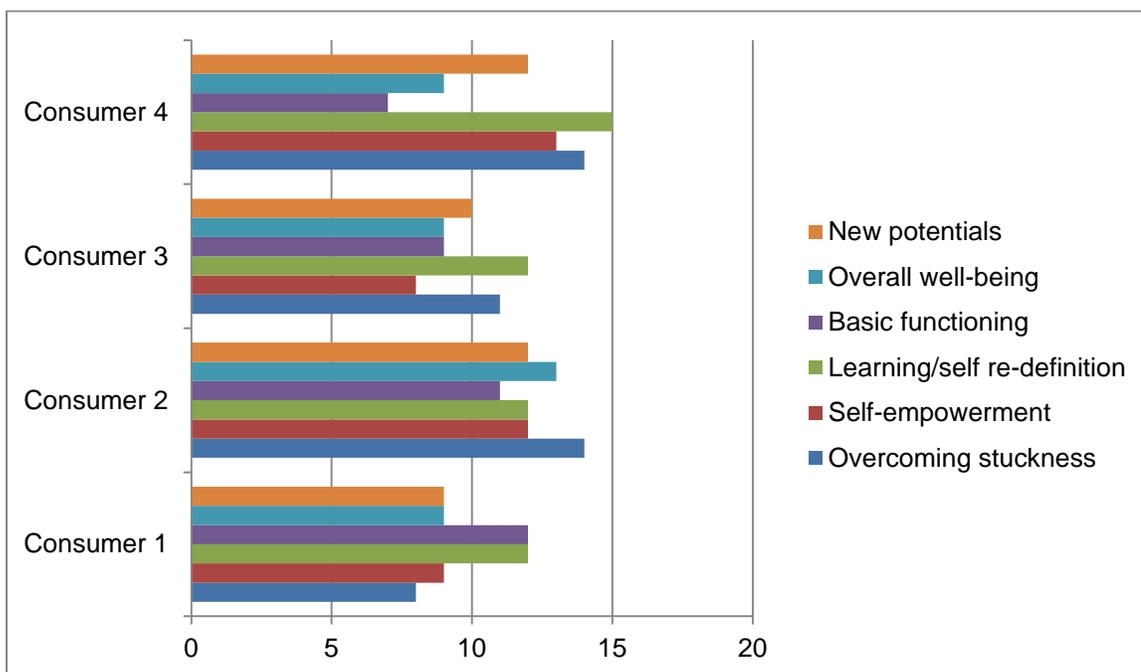


Figure 7: Mental Health Recovery Measure (MHRM) Subscale Scores for Consumers. This graph illustrates the personal recovery beliefs of consumers across cases (Young & Bullock, 2003).

Within the RAQ-21 two factor subscales, consumer 3 (Sean) scored highest in his beliefs that “recovery is possible and requires faith” and “recovery is difficult and differs among people” (*Figure 8*). Interestingly, consumers 1 and 2 (Dan and Rebecca) scored equal to one another for both of these categories; whereas they could not have been more different from one another in their narrative views. Alison scored next to highest in both

of these categories. All consumers in the study scored higher in the category of “recovery is possible and requires faith” than “recovery is difficult and differs among people.”

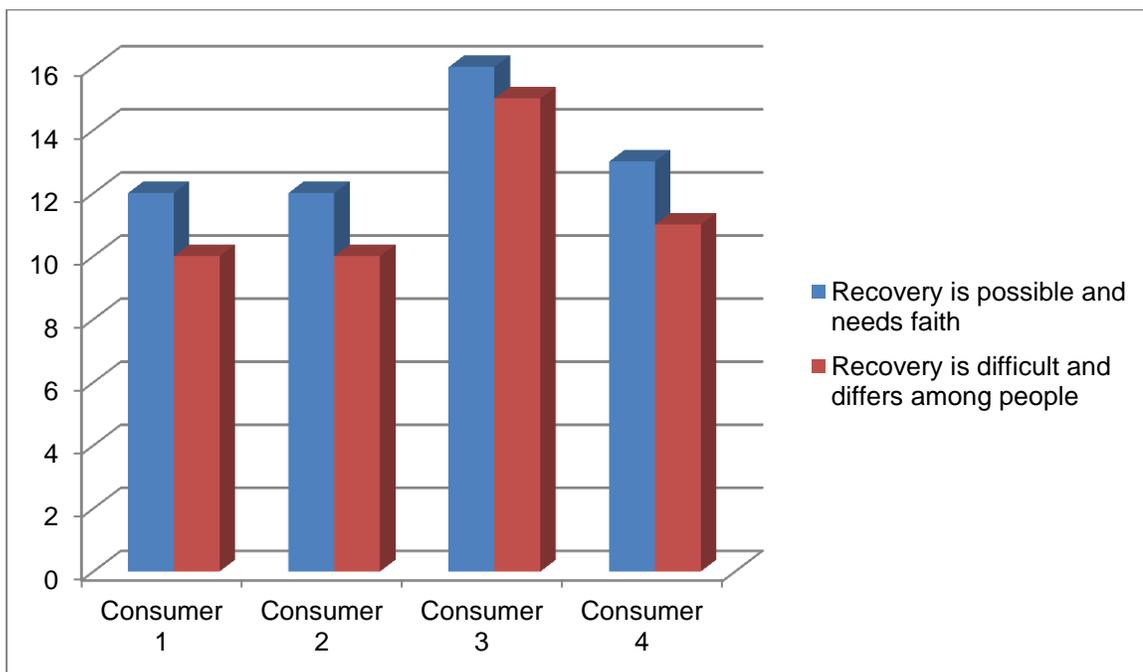


Figure 8: Recovery Attitudes Questionnaire (RAQ-21) Factor Component Scores for Consumers. This graph illustrates the general recovery attitudes of consumers across cases (Steffen & Wishnick, 1999).

### Family Vignettes

#### Case One: Sheila (Dan’s mother)

*Sheila, age 68, is the mother of Dan. She lives locally to her son, in an apartment she shares with her second husband whom she met while in the Peace Corps. He moved to America to be with Sheila, and they will soon be working toward bringing her husband’s daughter to America. Sheila also spends time each week as a “surrogate grandmother” to twin babies of a single mother from Guyana. Sheila has hosted Dan in*

*her home at times during his illness when he needed extra help. From the very beginning of his illness, she has been his primary family support. Sheila suffers from clinical depression herself, relying on lifestyle adaptations rather than medication to manage her symptoms. She has one other son who lives in California, whom she was preparing to visit at the time of the interview. Sheila and Dan see each other frequently during the week, particularly for the purpose of exchanging the vehicle they share. They also have dinner together about once per week. Sheila works part-time as a research scientist in immunology, and was eager to share her story for the purpose of advancing research in the field of schizophrenia.*

Sheila met with the researcher for one main interview in-person (March 2011) and one telephone verification (August 2011). The in-person meeting place was serene, next to a fountain outdoors, chosen by Sheila. She arrived to the interview with freshly painted lavender toenails and disposable flip-flops, obviously having just left her spa pedicure! The audio-tape was still clear amongst the sound of running water, and the conversation was easy and natural.

### **Case Two: Maureen (Rebecca's mother)**

*Maureen is the 59 year-old mother of Rebecca. She was also known from a previous clinical relationship while Rebecca participated in voluntary research and clinical medication trials. She lives with her husband in the same house where she raised each of her three children. Rebecca is temporarily living with her mother and father until she is financially and emotionally able to live on her own. Maureen prides herself in her work as a realtor, working long hours. However, she shared at the beginning of this interview that she has had to shift her priorities in the past year to help her daughter*

*with managing her treatment. She also enjoys being active and the stimulation of variety at work.*

Maureen met for one private interview in a conference room at her place of employment in April 2011. She verbalized that she was excited to share her experiences, and was thrilled that someone was interested in hearing it. She had already prepared some of her thoughts in her mind about what she knew she wanted to get across during the interview. She devoted a couple of hours to the interview with a few brief work-related interruptions. Since this was a familiar relationship for both researcher and participant, conversation began and continued quite naturally. Since time ran over at the end of the audio-taped interview, Maureen agreed to send the recovery questionnaires within the week following the meeting. The telephone verification interview was completed in September 2011.

### **Case Three: Paul (Sean's father)**

*Sean's father, Paul (age 59) participated in the study to share his experiences with his son. He divorced Sean's mother when his son was a young boy and eventually re-married his current spouse. However, during the verification phone call, Paul revealed that he and his spouse were separated and in the process of divorce. Sean moved to be near his father approximately 17 years ago. He lived with his father initially, until Paul put him out of the house when Paul's illness spiraled out of control. After a long period of homelessness, his son finally accepted treatment and was able to live on his own. He and Sean now live in local proximity to one another and meet at least weekly for breakfast and watching sports on television together. Paul identifies himself as a recovering alcoholic, who has recently celebrated 15 years being sober. He also*

*lives with a chronic autoimmune condition, Multiple Sclerosis, for which he takes medication. He is currently unemployed.*

Paul met the researcher for an in-person interview at the consumer-run mental health program where his son attends. He walked with a cane for support, and was observed to be easily out of breath from the walk across the street to the building. He was cheerful and seemed to look forward to talking about one of his favorite subjects, his son's hard fought victories. Paul openly shared his thoughts about his son, his views of medication adherence, family roles, and vision of recovery. The follow up phone call interview was completed in October 2011, where Paul reported that he and his current wife were in the process of divorce.

#### **Case Four: Richard (Alison's father)**

*Richard is the 66 year-old father of Alison. Richard is a retired attorney who worked for the U.S. Government. He has lived with schizophrenia for the last 34 years, experiencing previous involuntary hospitalizations related to periodic relapses. Richard did not adhere to medications until the advent of newer generation antipsychotics in the 1990's. He did not take medications in the past because they did not permit him to think clearly and stay alert at work. He raised his son and daughter, sometimes with his late wife's parents' assistance, and at times on his own when he was more able. He managed his own illness by working until he relapsed, going into the hospital to stabilize with medications, and taking leave from work until he decided that he was healthy enough to come off medications in order to return to work. Richard is a unique profile of both consumer and family member in this study, taking care of himself while also trying to*

*help his son and daughter, both diagnosed with schizoaffective disorder with bipolar features.*

Richard came along with his daughter to the drop-in center for his interview, patiently waiting while Alison was interviewed first. He ate his lunch and socialized here and there with some members of the center. His daughter was cordial as she introduced him to some of the others. He appeared comfortable during the interview and seemed to enjoy showing his pride for his two children, particularly in what they have been able to overcome in life with their mental illnesses. Richard offered a unique perspective as both a consumer and family member, as he shared quite openly about his own life and his experiences with providing support to Alison. After the interview, Richard asked for a ride to his home as he did not have transportation. He proudly pointed out his regular route for daily walking and the plants that he had taken care of in his yard. The verification phone call was completed in October 2011.

### **Family Views of Consumer Medication Adherence**

Family members across cases shared the vision that their adult children not only required medications, but there existed an *absolute necessity for psychiatric medications* to manage their schizophrenia or schizoaffective disorder. Sub-themes that emerged from family perspectives regarding this topic include: a) family beliefs about medication, b) perceived rationale for consumers' non-adherence, c) perceived rationale for consumers' adherence, and d) family observations of medication effectiveness.

## Absolute Necessity for Psychiatric Medications

### Family beliefs about medication.

One of the ways in which families tended to express their perspectives about medication is through comparison with their own illness, and/or physical versus mental illnesses. Sheila revealed her own struggle with clinical depression, deciding to rely on other strategies for healing instead of medication:

Sheila: *“I think my illness isn’t as overwhelming or as acute as Dan’s is all the time. So there are times that I feel like I can get by without changing my chemistry...Because I don’t trust drugs (laughing) and I know I don’t trust the ones that Dan’s on and he doesn’t trust them either but it’s just something he has to do. Whereas, yeah, I have the choice at this time. I might change my mind if this doesn’t go away soon and that’ll be the key if I’m feeling this way for a long time I’ll go ahead and take the medicine.”* (p 6)

She explains further her rationale for choosing a non-medication route:

Sheila: *“[I didn’t choose medication] I would say primarily side effects. Off and on I’ve taken medicine. It’s worked and sometimes it happens and it doesn’t. And I was on Wellbutrin for a number of years and then I became sensitive to it and couldn’t take it anymore. So I thought that was actually very helpful but when I became sensitive to it I tried another one or two and it just wasn’t good. It wasn’t successful so I just decided to try and live with it, which is a silly thing to say when you have an illness like that. Like I say to Dan, you know, it’s just like diabetes, take the medicine, don’t fuss. Why fight it, and yet I’m the one who will say ok well I will try not to because I don’t want to deal with it you know!”* (p 6)

Sheila has experience in the healthcare arena as she has worked in the research science field. Through her work and personal research on behalf of her son, she has come to distrust medications, which she refers to as “chemotherapy drugs:”

Sheila: *“Because I participated in a number of clinical research trials and I know exactly what goes on and I know exactly what chemotherapy is. And I know particularly with psychiatric medicine they’re dealing with, throw the drugs at them and not understanding the cellular components and the genetic components and all the important things that have to do with illness. So it’s what we have available now, but I think it’s a shame the way that it’s treated and the lack of knowledge about the topic.”* (p 6)

But Sheila knows Dan needs them despite her mistrust:

*“Absolutely it’s a very, very difficult illness to deal with, and it does help him deal with it to take medication. That’s obvious, and he knows it’s obvious.” (p 7)*

Maureen also engaged in a comparison of her own depression and anxiety issues with her daughter’s illness and need for medication. She also explains why she chose a non-medication approach:

*Maureen: “But I went through a period where I was depressed, I had trouble sleeping. I had trouble doing things, you know. I didn’t, I think I went to a psychiatrist once after I was married...but it was so expensive and I couldn’t get it on my insurance and that sort of thing. So I just stopped. And being a very self-reliant person, brought up in a very self-reliant family, I said well doggone it, I’ll work my way out of this myself [laughing] ...I never took medication for it. One of the things that I found really did help and that’s why I’m such a fanatic about exercise right now...the main thing you want to do is you want to start exercising more regularly, you want to stop, slow down on the caffeine. You want to slow down on any booze and that sort of thing...”*

Sean’s father also lives with an illness, multiple sclerosis. His views of medication for himself rival his views of medications for his son. In fact, he talks with his son openly about his use of medication and the joys and struggles of having medicine for his illness:

*Paul: “I’ve always had faith in him, you know, and if you do the right thing, I have to bring up examples of doing the right thing to him and let him know he’s on the right path, especially when he started medication, and there was a noticeable change in his behavior. I said, ‘see what happens when you do the right thing?’ ...you can see the changes in your life, you know, and I take medication as well...sometimes because of the side effects of this medication I’m taking for MS, I get really discouraged but I think about what would happen if I wasn’t taking this medication for MS. I’d be in a worse situation.” (p 27)*

Richard’s beliefs in medication are unique in that he is also a consumer who has lived with schizophrenia for over three decades. His perspectives have changed through the years, as he chose a non-medication course for much of his young adult life while trying to work and raise his children. For the past seven years, he feels that he needs

medication just as Alison does. He reveals more about why he did not take medications earlier:

Richard: *“And I was struggling with the medication they were prescribing Navane which is a current major tranquilizer and Desipramine and I mean had me lethargic all the time. You know it was hard to think, but I said, I told them, I said, you know, it’s very difficult for me or carrying a train of thought, and they’d say, you know we have to give you this because to keep out all these other influences you need this tranquilizer. So I don’t need that anymore... My reactions? Yeah, I guess it did, you know I guess I had progressed to the point where it was really just hampering my capabilities...”* (p 12)

He also reveals a fear that he maintained for some time about his medications:

Richard: *“Well, when the last time I was in the hospital, I thought it was like made out of horse manure, the medicine.”* (p 27)

#### **Perceived rationale for consumers’ non-adherence.**

Family members revealed their own perceptions of why their adult children were non-adherent to medications. Even in cases where their adult child adhered to medications, such as Dan and Alison, parents brought their concerns and disappointments to the forefront. Paul reflected on Sean’s long standing non-adherence while he was homeless:

Paul: *“The first time he got out of the hospital, I’d picked him up and he told me in the car that he wasn’t going to take it, no medication. ‘I’m tired of getting that’ because they gave me a script, a prescription and we might as well pick up the medication on the way home. He said ‘I’m not taking that. Who you getting that for, yourself? I’m not taking it...’ I got the medication and I said well, maybe he’ll change his mind. So if he does change his mind I have the medication here. He never changed his mind, you know.”* (p 41)

Richard recalled Alison’s grief over not being able to go into the military around the time that she tested out non-adherence to her antidepressant medication:

Richard: *“Yeah she did because when she was eighteen years old, she wanted to go into the service. It might not have been too bad at that time, like it is now, they don’t send you into the meat grinder, forthright, forthwith you know like they do now. It might have been pretty nice at that time when she was eighteen to go into the service, but I remember*

*she was very despondent thinking they don't want her, you're taking medication, you ain't going into the service. So, she is quite crest fallen over at because I don't know if she wanted to go to college right away, you know."* (p 25)

He was also aware of her concern over unwanted side effects:

Richard: *"Hmmm, could be because I think it contributed to her tendency toward being overweight. Medicine will do that, you know."* (p 26)

Maureen explained that Rebecca did not take medications for schizophrenia initially because she did not agree with her diagnosis. Instead she thought she had Attention Deficit Disorder. When she did agree to take Risperdal, Maureen explains that she took it in order to engage in productive life again, but the outcome was not as she would have liked:

Maureen: *"She took it for a while; she was out trying to get a job. I noticed she was taking it on a regular basis until nothing materialized with any of her efforts and she stopped. I said this isn't helping... the medicine was supposed to help, you know. Help her think, you know, to cope, to get a job. I mean this is how she looked at it, to get her friend, her social situation together. Not helping, stop medication. Not making me feel good anyway."* (p 17)

Maureen was also cognizant of Rebecca's concern over side effects:

Maureen: *"So things just got worse, you know and she wanted to go back to her condo, she wanted to live alone, she was going to try and get a job on her own, but you know as she did that, you know she wanted to stop the medication and she did...She went to the gynecologist and came back and said 'the gynecologist said I should stop taking the medication, it was messing me up.' So she stopped and when she stopped it the last time, then everything broke loose. I mean super crisis..."* (p 21)

Maureen: *"One of the reasons, I think the side effect that bothered her the most about Risperdal is the fact that it disturbed her menstrual cycles...she said 'this medicine is making me sterile' she said, 'and I want to have children.'"* (p 19)

Despite Dan's persistence in adhering to medication, Sheila has heard him express concerns over the effects of medication on his sense of self:

Sheila: *"He has said 'I wish I didn't have to take the medicine' and he has said 'I don't want to add anymore, and I don't feel myself when I'm taking this medicine.'" (p 31)*

*“And sometimes he’ll say to me, ‘do you recognize me? Am I the same person?’” (p 31)*

Although Sheila would like him to consider adding another medication for his mood problems, Dan does not want to take any more medication:

*Sheila: “I know this time I wish he was on an antidepressant because I think that that’s a very large component of what he’s going through and he refuses to take any more medications. He says he’s taking enough.” (p 29)*

When she was asked to discuss her insights about Dan’s rationale for not wanting to take too many medications, she said:

*Sheila: “I think he’s taking three. He doesn’t want to take more. I can understand, it’s too bad that there isn’t one that works, but I know this is a very complicated illness and they just don’t know enough about it to treat it.” (p 29)*

Dan also shared with his mother that he does not like the side effects such as arthritis, paranoia and headaches. These side effects also fluctuated on other medications:

*Sheila: “I think he’s always felt like there was nothing that removed his symptoms completely, but it was a constant battle that he has to constantly re-interpret everything that’s coming into his sense, whether it’s sound, smell, voice, things around him. He’s always re-interpreting constantly because if he doesn’t, he gets wrong information.” (p 29)*

In the follow up interview with Sheila, she reported that Dan was recently reading more about people who choose to not take medications for schizophrenia. However, he still decided that he needed to stay on his medication.

### **Perceived rationale for consumers’ adherence.**

Parents in this study also spoke extensively about their opinions of why their children chose to adhere to medications. Paul feels that Sean links his medication to better function:

Paul: *“I think that he feels that, he realizes that it’s needed. He’s not crazy about the perceived side effects, putting on weight, getting big, making him lethargic, sleepy. He’s not crazy about that, but I think he’s come to a point where he realizes in order to function, he has to take it.”* (p 13)

He explained that he thought Sean must have had a moment of clarity when he decided to take medications after many years:

Paul: *“This last incarceration seemed to have had...wow, you know, it’s like in alcoholism, when people decide to go and to seek help for alcoholism, they say well he must have had that moment of clarity. You say ‘I’m killing myself out there; this is not the way to go.’ I don’t know if people are confronted with mental health issues have that moment of clarity, maybe this ain’t the way for me to be functioning.”* (p 41)

When asked whether and how Paul knew this time was different for Sean, he replied:

Paul: *“After he began taking his meds and he’d make a point to let me know he was taking his meds, you know. There were times when he made it a point to let me see him actually put the pill in his mouth, and he’d never done that before. He probably had been cheeking his medication before, but when he made it a point to let me know he was taking his medication...Yeah, it was different. I don’t know if I had thought he turned a corner, you know, but it was different.”* (p 44-45)

Despite the barriers Dan has faced throughout his illness, he has regularly adhered to medication. Sheila and Dan’s explanations for his regular adherence to medications rival one another in their impressions of fear’s role in his decision:

Sheila: *“Well, primarily he knows what he’s like when he’s not taking the medicine. And for him, that’s terror. He is afraid to death not to be on his medicine...”* (p 23-24)

She went on to explain what has influenced his stellar adherence to medication:

Sheila: *“I think first of all, it’s his intellect. He’s smart and I think that he figures out what’s better for him and follows through with it. The second thing is, I think that depending on the medicine and the time, sometimes it’s been very beneficial and he’s recognized that, and so that’s an impetus for him to keep taking the medication. I think that even the little pill box helped...he keeps it in his bathroom, yes. So that when he brushes his teeth before he goes to bed at night or when he gets up in the morning, the pill box is there and he’s aware of it being there.”* (p 26)

Interestingly, Sheila also used the idea of Dan's moments of clarity in seeking help for himself during crises:

Sheila: *"I think that he had moments of clarity because he was trying so hard to get some kind of medicine because he knew that things were just going really bad...he is afraid to go to the hospital, any hospital, because he's afraid he'll never get out. So for him to decide to go to an institution for help means that he's really in a crisis...he knows that at that point that's about all he can do."* (p 24)

She explained her son's continual accountability to his medications as he manages illness:

Sheila: *"Yes, yes I think he does use [the pill box] and he is very conscientious. He'll be over at our house at night and it'll get late and we'll have had dinner and watched a movie or something and I'll say 'well, why don't you just stay?' He'll say 'no, I have to go home and get my meds.'" (p 19)*

In addition to his awareness, Sheila feels that Dan has tried to communicate his desires with his providers:

Sheila: *"Well, I think it was his feeling that he needed to take medications that brought him back and it's been the impetus for him if he was having certain difficulties with symptoms or side effects that he would try to get some adjustment and go to the doctor and say 'this is happening, what can we do about it?'" (p 26)*

Maureen thinks that Rebecca takes her new medication, Abilify, because she realizes she needs it:

Maureen: *"She seems to be very responsible for [taking her Abilify]. I think she's pretty much, I mean even though I do think it keeps her from losing weight, it doesn't help her keep her weight down, I think she realizes that she needs it and she should take it and she's going to a therapist on a regular basis..." (p 32)*

She also explains her take of Rebecca's experience of side effects. Notably, she also feels that Rebecca's newfound adherence may have links to a trusting alliance with a provider; one without family ties as in the past:

Maureen: *“I’m going to make a couple of guesses [laughing], just guesses. When you talk about, this is well the side effects of the Risperdal you know. I don’t know what it feels like to take Risperdal, but I understand it zaps your energy some, you don’t feel very energetic. I understand that it has some kind of effect on your hormones so that you don’t have regular menstrual cycles, which can be disturbing. With the Abilify, frankly, I read the side effects of Abilify, I don’t remember what they are, but just the fact that she is taking it on a regular basis and not having a problem with it. And she said she feels better having taken it than not taking it makes me feel like the side effects is you know, not the same... Okay, the other thing is, which I believe is psychological, is that those professionals that prescribed the Risperdal for her, she viewed in some kind of negative way. The people at [the research hospital] she liked and she’s felt that that was a, and she used these terms, supportive environment, okay... She gained a lot of confidence in the therapy, the medication, the whole process while she was at [the research hospital...” (p 33)*

Maureen explained that Rebecca seems to take full responsibility for managing her

Abilify, including expressing her needs with her doctor:

Maureen: *“And the psychiatrist last time she thought that maybe she would cut back some the next time on the medication. Rebecca told her last week that she didn’t think she was quite ready... so that was an indication to me that she thinks she needs it. When she was running out this week, she reminded me she needs to go to the drug store to get the prescription we needed, so we did that yesterday. Drug store didn’t have the right dosage, and said they’d have to order it and she said ‘gee, but I think I only have one left and I said ‘well, why don’t we go back home and you need to check to see how many you have?’ And she said ‘oh good, I only have three, I mean I do have three so I can make it until Monday when they order it.” (p 32)*

Richard did not offer his opinions specifically about his daughter’s adherence, but focused on his own experience of a decision to adhere to medications:

Richard: *“And so I wouldn’t take it. And she said I’m giving you this, she didn’t say you better take it or anything, but I took the bottle, it was [inaudible] and I took it home and something told me just take it, you know, so I started taking it and I’ve brought myself to the realization that I better do something about my finances too. So I took care of all my finances right there in December 2004 and 2005, I had fallen down in my mortgage payments and all that kind of stuff. Of course, you can’t pay it when you’re in the hospital. I was very concerned about all my bills when I was in the hospital. I couldn’t pay any of them, you know... I didn’t have my checkbook and Alison, she wasn’t coming to see me and they don’t give you an opportunity to do your bills or anything, or pay your bills or anything... I just thought of that Indian [doctor], and like that girl was telling me, it’s not a hotel, you know. . But something just told me take it, maybe it was the Holy Spirit maybe told me to take it, so I started taking it.” (p 27-28)*

### **Family observations of medication effectiveness.**

Families described their observations regarding medication efficacy for their children in distinct ways. Although at times Maureen questioned Rebecca's past medication efficacy at times, she reports noticing an overall benefit. Asking Rebecca about whether she took the medication did not usually go well, however:

Maureen: *"I just, you know and when she had it, it seemed like she was improving... [what did I notice?] let me see, other than seeming a little bit more normal. What is more normal? More normal is thinking more logically, more organized thinking...it was just that being able to finish a task, being able to converse in a logical manner and with organized thinking, I mean nice thoughts. What you would expect of a college graduate in terms, and what you would expect of someone who'd had the successes that she'd had, okay...when she wasn't on the medication and she was you know thinking and doing things that didn't make a lot of sense or didn't seem to be helpful to herself, I would start asking 'did you take your medication this morning?' ...and that would start a battle sometimes about that, yeah the medication and why she didn't want to take it..." (p 19)*

Maureen recalled Rebecca's response to her current medication regimen:

Maureen: *"So, you know once they started her on [Abilify], things just seemed to get a lot better and she was calm and more organized thinking..." (p 27)*

She feels that many serious symptoms of her daughter's illness have been helped by the new medication:

Maureen: *"If you have me the list of symptoms for disorganized schizophrenia, she had them all okay? Loose associations; let's see what can I remember? That was one of the biggest ones. I mean everybody that she knew whose name was John was automatically related. It's John you know, they must have seen each other recently, because they're cousins, right? Yeah, uh huh. That was really bothersome and the inability to make good judgments and cozying up to people who were complete strangers...that person looks like a friend of mine...And [delusions about] hair length and Afro hair styles and all this, oh and this whole business of the obsession with long hair. She still hasn't gotten quite through that, you know, she still adds on extensions to her hair because she thinks it's better, but she's not so obsessed with thinking that people with short hair are sick." (p 27-28)*

Though Paul felt that Sean has improved greatly on his medications, he pointed out a difference in his social tendency:

Paul: *“Yeah, I think, basically, he’s a shy guy. He’s very shy. What I’ve noticed is that when he’s not on his medication, he’s a little bit more outgoing, you know, a bit more courageous, but when he’s on his meds, he’s somewhat subdued, you know.”* (p 30)

Sheila expressed her opinion about Dan’s function on his newest medication regimen, which includes Clozaril. Although Dan feels it has been a good medication, Sheila has noticed cognitive decline:

Sheila: *“To tell you the truth, as far as Clozaril is concerned, Dan says that he feels that it did a good job for him, that he thought it was helpful, but I have noticed as I said, since the time of his last break, that intellectually he’s not as acute and that he doesn’t remember things and that he can’t make sense of what he’s thinking and sometimes he’ll say things that are so out of the blue and out of context...”* (p 31)

Although Sheila thought he was still himself, overall, she had to admit that she wondered about medications causing unusual behaviors in her son:

Sheila: *“And in reality, he is, but it’s very difficult to describe what the differences are. One or two times he got very angry with me, very livid and red-faced and angry and I was afraid...but I was wondering if it was because he was on a different medication and that was bringing that out...he’s so gentle and thoughtful that to see that was very scary.”* (p 31)

The researcher commented on how this would be challenging to try and tease out what would be related to medication versus other circumstances. Sheila wholeheartedly agreed:

Sheila: *“Yes and then just feeling free to get angry if he wanted to be angry for heaven sakes, I mean it’s okay to be angry...”* (p 32)

### **Family Roles as Social Supports**

Parents of young adult children living with schizophrenia or schizoaffective disorder endured their own processes of understanding their child’s needs and responding within their supportive roles. The process was dynamic and complex, focusing on the family’s *puzzling dance of support and separation* as they parented their young adult children. Some roles dealt directly with medication management, but many involved

support in a broader sense of illness management. The subject matter involving this all but straightforward dance included sub-themes of: a) stepping in for emotional and practical support, b) stepping back, c) guilt and isolation, and d) culture and family ways of life (*Figure 4.5*).

An additional theme was uncovered in the analysis of family data in this study, which centered on *the abyss of family-provider discourse*. Families shared their passionate ideas and mixed impressions of their interactions, and lack thereof, with providers concerning medication and illness management for their adult children. Sub-themes incorporated the following aspects of discourse: a) exclusion from consumers' health care, b) disappointing responses from providers, c) positive experiences, and d) advice to providers (*Figure 9*).

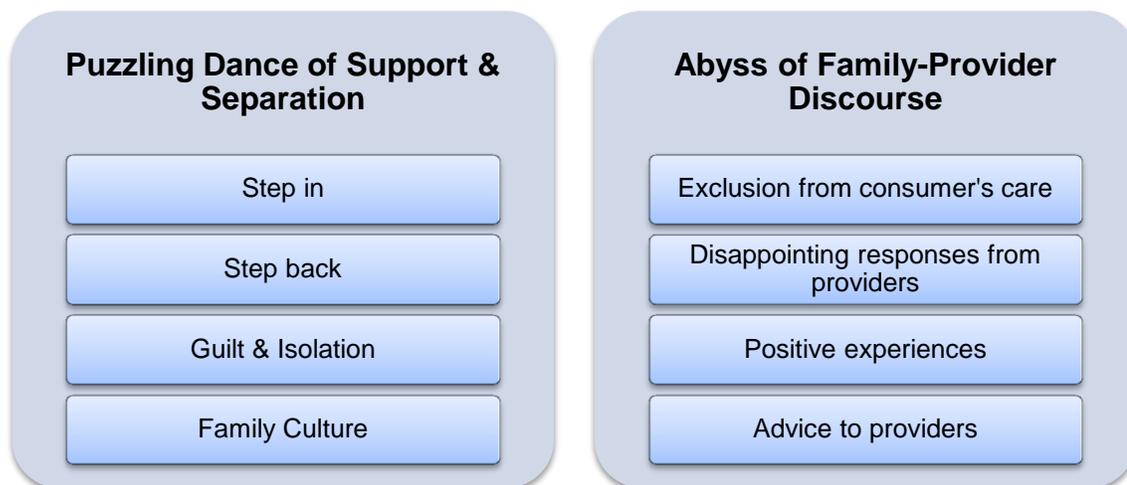


Figure 9: Family Roles as Social Supports. This figure illustrates features experienced by families in their relationships with adult children with schizophrenia or schizoaffective disorder as well as their children's treatment providers.

### **Puzzling Dance of Support and Separation**

Families in this study underwent varying degrees of dancing in and out of their adult children's lives. It did not seem to be the case that families did not want to "naturally" separate from their children in order to allow them to experience life on their own for the first time. It was more the case that they could not. If they could, it did not seem to be long lasting.

#### **Stepping in for emotional and practical support.**

As mentioned previously, parents in this study played a variety of roles in support of their children. Some dealt directly with medications and adherence, and others were less directly medication related and more focused on general illness management. This section will review medication, emotional, and practical support roles of parents with their adult children.

**Medication Roles.** Parents in this study were involved with medication management roles in a few ways. Some were more involved than others, and some described past involvement that eventually changed. Maureen was excluded from much of Rebecca's healthcare decisions, with the exception of times when her friends or acquaintances became Rebecca's doctor. Since her daughter did not accept her involvement, Maureen was left to be an observer. She describes her experience of collecting various medication containers in order to help inpatient doctors figure out what medications her daughter had already tried:

Maureen: *"When we were helping her to get her room straight, and trying to you know clear up and organize and that sort of thing, I was collecting these box, you know I'm seeing these medications here and there. And so I just collected them all. I said something is not right. I'm going to collect these all and put them away. I mean she's not taking them anyway, at least I'll know what she's had...when I got more involved in a*

*situation, I would write down the dosage you know, I wrote down all the information...[Staff] called me from [an inpatient psychiatric unit] and said, 'well, we're trying to figure out what to give her. What has she had?'" (p 18)*

Maureen handled the role of giving her daughter medications each day for a while after she was hospitalized for a crisis:

*Maureen: "I was giving it to her every day to take and as I just, you know, I could kind of tell some days that it didn't seem like she was under medication and I'd ask her. She said she took it, but I caught her hiding it and cheeking it a couple of times. I found little pills here and there." (p 25)*

When she found out that Rebecca was not taking her medication, she spoke to a niece of hers who was a clinical psychologist. She informed Maureen of options to help with adherence:

*Maureen: "I found out there was a kind that you could get that dissolves instantly once you put it in your mouth. Okay, I said, well, can you prescribe that for her so we'd be sure she gets it? And she said it's very expensive and I said, at this point I will pay my last nickel to get this medicine so that she can be at least stable until we get her to the research hospital, so she called in the prescription.." (p 25)*

The dissolvable pills did not work out as she had hoped, due to a glitch in the prescription dosage that affected Rebecca's willingness to take it:

*Maureen: "She gave a dosage that they didn't have and I had to go all over the place to find the medication or they had to order it and that sort of thing. And then I finally got it and Rebecca wouldn't take it. That all went to hell. Oh, I know, they didn't have the single pill in the dosage that she recommended, so she had to take two, but yet the doctor had prescribed this pill and I called her and I said 'this isn't the right amount. I think you know this isn't the same amount she's been taking. It's like half' and she said, 'oh well, give her two.' I said 'well, I'm having trouble giving her one. How the hell do I get her to take two?' [chuckling] ...So I tried to give her two..Rebecca said 'well the box says one' and I said 'oh shit!' I was so aggravated." (p 26)*

Paul did not take a direct role in medication management for Sean, but shared his own experiences with medications while helping to point out changes in his son:

*Paul: "I've always had faith in him, you know, and if you do the right thing, I have to bring up examples of doing the right thing to him and let him know he's on the right path,*

*especially when he started medication, and there was a noticeable change in his behavior. I said, 'see what happens when you do the right thing?' ...you can see the changes in your life, you know, and I take medication as well...sometimes because of the side effects of this medication I'm taking for MS, I get really discouraged but I think about what would happen if I wasn't taking this medication for MS. I'd be in a worse situation." (p. 27)*

Sheila spoke about her initial role in helping Dan with his medications, which included a mix of practical tools and educational advice:

*Sheila: "Well, in the beginning I was very aware of the medications and I was doing research on what the latest information was and how long things had been tested in England or in Europe just to make sure they knew what the side effects were. And I was doing a lot of work on that level and I knew everything he was taking and I knew what was going on with the changes. And then I also bought him a pill box because I was worried that he'd forget..." (p 19)*

Richard was also involved with medication management for Alison in the past while she was living with him. He reflected on his own difficulties as a result of non-adherence, and shared it with Alison. He also took on a role of reminding her to take her medication:

*Richard: "Yeah. You know I would be.... I would....and that's when I would really have problems [when I didn't take the medication]. That's why I tell Alison don't ever change your medication or stop until unless it's under the doctor's advice... Like when she was living with me, I would remind her in the mornings, and she'd say, I forgot it; I'd say, don't forget it. Take it. Now that she's not living with me, I hope she's taking it or that's she's curtailing it under the advice of a doctor, but I don't know. Alison wanted to have a child, you know, or maybe two if anybody can afford even one today, but she would have to do that under her doctor's advice you know." (p 14)*

Interestingly, Richard's children took on a reverse role in trying to help their father with his non-adherence to medication. Richard recalls responding non-favorably, however:

*Richard: "Yeah, well they've always coming in there when I was having problems from when like one time I retired September 2003 until December 2004; I was not right during any of that time. That's when I was giving fifty dollars to people, fifty dollar bills you know and I was going to the ATM everyday for 700/800 dollars just I don't know where it was going. And they were very concerned and they'd come over and did you take your medicine, you know? And I didn't have any intention of taking it, and I would just say,*

*something confrontational with them, you know and I remember one time that I tricked my son, he came over and said, did you take your medicine? I want to see you take your medicine tonight. I said well, somehow I got him to go outside and I locked the door and I wouldn't let him back in. [CHUCKLE]" (p 27)*

**Emotional Support Roles.** Emotional support was displayed in numerous ways by parents, whether it was in the form of knowledge-sharing, advice, positive encouragement, problem-solving, or pride. Even while he was homeless, Paul tried to help his son by hosting a medical appointment at his house. He wanted to find a way to help his son get out of the pit of despair. However, the outcome was not what he had hoped this time, which led him to allow Sean to walk out again:

*Paul: "He came here for an assessment one time, and he was really sick...he just wasn't feeling it and there was a young guy here, I guess he was a psychologist, and he was asking him questions and everything was my fault. This lying SOB over here, I'm lying, you know, and I said 'well, son, if you don't want to be here, you're wasting everybody's time.' He got up and walked out..." (p 23)*

Paul's dance took place within the unimaginable context of continual worry about whether his son was still alive. During Sean's homeless period, Paul would stay in contact with him as best he could, without having any way to know where he was staying or even if he was in the local area:

*Paul: "Even though he was homeless, he and I always stayed in contact with each other...actually, I just went to [the city] and I sought out the homeless shelters and I just went in and started asking questions...It was difficult...[When I finally found him, I thought] 'he's safe.' Whew (CRYING)." (p 21)*

After Sean finally accepted treatment, Paul has continued to offer his emotional support for his newfound practice of Buddhism:

*Paul: "I think it's terrific. He's found something that he likes, and he has his little altar in his home where he does like his meditation in the morning, you know and it's terrific...if he drives all the way to [location] to practice Buddhism, he's serious about it." (p 30)*

*“Well, I tell him [I’m proud of him]. He doesn’t ask, I just tell him. You know I told him yesterday.” (p 45)*

During the follow-up interview, Paul explains that he and Sean keep their conversations “regular.” He stated, “every time we interact it shouldn’t be about the mental illness.” He does admit that relapse can always happen, knowing from experience that staying sober is no easy feat. “The only thing I can do is hope and pray [that he continues treatment]. There are no guarantees.”

Sheila has been an active support in Dan’s life, using her professional knowledge and personal talents to acquire evidence with all things medical. When she was asked about her sense of using both her professional knowledge and her “parent” wisdom to manage Dan’s needs, she replied:

*Sheila: “Well, I think there has to be [different perspectives] because there isn’t the same knowledge, the same intimacy that I feel I have because of my son but it is so complicated. Too much, too much empathy, too much interaction is not good either and it’s very difficult to choose where that line is...I don’t know how people who are not well-informed can deal with something like this, and I have seen people who aren’t. People whose children are in this situation and they are at a complete loss of what to do and at a complete loss of understanding and I just, I don’t know how people deal with it.” (p 10)*

Perhaps one of the more discussed roles in managing Dan’s needs was the emotional support that she offered during challenging times. One of these periods was at the beginning of his illness, when he had to leave high school due to symptom severity:

*Sheila: “The way I’ve seen it is it takes awhile, it’s not one of those things where you can say ‘okay, then tomorrow you’re going to school whether you like it or not and that’s going to make you feel better if you go to school.’ It seems to be that it took time for Dan to rest, to even get his mind in order, to get used to thinking what it was like being in this new emotional state before he could make progress with other things outside of himself. So I tried to give him time to do those things at the same time as I tried to let him know that school was available, that there’s this, or that, or the other if he wanted to do it...” (p 11)*

In the past, Sheila also served as a reality check when Dan’s psychotic symptoms reared:

Sheila: *“Not so much the last three or four years, but before that, I was his reality check. I mean I remember one time we were going to the airport to pick up his brother...it was just terror to him that something was going to happen to his brother and he had to say, ‘oh, mom did you see that [plane crash]? What’s going on?’ And I’d say, ‘there’s nothing out there dear, everything’s fine...no dear, there wasn’t a crash.’”* (p 29)

*“Sometimes he had to say something to me like ‘those people are watching us mom. Are they paying attention to us?’ And I’d say ‘no dear, they’re just having their dinner.’”* (p 30)

Sheila also worked hard to stay positive for Dan and help him solve problems, even when she observed him to exhibit symptoms that elevated his grandiosity:

Sheila: *“He graduated and then started working, always feeling a little bit manic, a little beyond what I thought was a level that he should be trying. A little bit too self-confident, a little bit too grandiose in his ideas of what he was going to accomplish and I felt uneasy about that. And yet, how do you tell your son, ‘oh, no don’t aim for that, it’s too much.’ You know you can’t really do that. You have to say, ‘well, do you feel comfortable with this? Are you sure this is what you want?’”* (p 12)

Maureen visited her own psychologist in order to work through her emotions and learn how best to support her daughter. She recalled past behaviors that Rebecca had done that caused her to be angry; that is, before she knew that her daughter was in the throes of developing a chronic mental illness:

Maureen: *“I saw a clinical psychologist, and this was probably shortly after we had gotten a diagnosis and I was expecting okay, so she should go to the therapist. She should take the medication and she should move on with her life and get a job. You know, and this is you know, it seemed clear to me...I guess probably it was in 2008 or something that I started to realize this was more difficult and more complicated than I thought it was going to be. And that it wasn’t, I had to really stop being angry with her because she wasn’t moving along this path the way I expected her to. That the things, a lot of the things she was doing, she was doing because of her illness and not because she was just being contrary.”* (p 13)

When Maureen worked through her personal acceptance of Rebecca’s diagnosis, she took on a major emotional feat; that is, helping her husband and other children to understand what was happening and to guide their interactions:

Maureen: *“And I found that I was the one that was most motivated to learn more about it, so I was the one that did the studying and did the research and talked to the people and got the information that we needed to get in terms of how to cope. And so I was the one who, because we were constantly, every family member was at odds with Rebecca and I would say, I realized what was going on and I’d say to my husband, I said ‘there’s no point getting angry, there’s no point in arguing, it’s not going anywhere, it’s the illness, you have to stop. It’s not helping.’ And I would stop him, and the same thing with her brother when he came back here to live...Because I knew she wasn’t on the medication, she wasn’t taking it. Even sometimes when she was taking the Risperdal, it wasn’t working it seems.” (p 14)*

Maureen’s involvement with her daughter increased in times of crisis, such as when Rebecca refused to take her medication. On the way to her outpatient psychiatry appointment, Rebecca jumped out of the car while riding with her mother:

Maureen: *“And when we stopped for a light in [the city], but as I think through it, my...I understand why she did and it didn’t occur to me right at the moment, but she was in a psychotic situation at that point, okay. She had been trying to get a job in [the city] and when we stopped at the corner for the light on our way to the doctor’s office, and I had to drag her out almost you know. I really had to persuade her hard to go with me to the doctor’s. When we stopped there, you know, she still had this ambivalence about going and she looked over and she saw this store where she had gone in and put a job application where she really wanted to work. And I think when we stopped she jumped out. I said, ‘Rebecca don’t do that, you’re going to die here’ and she said ‘leave me alone!’ and slapped me...” (p 23)*

Maureen was especially upset during this crisis, anxious for her daughter’s safety:

Maureen: *“Because I could tell she wasn’t right at the time, you know. She could very easily wander off and get lost. And I remember hearing stories about parents who had these sick kids and they disappeared and they’d gotten into trouble or they got on drugs...I said I don’t want her at this point, I don’t want to lose her...I talked to the police. I explained to them that we were on our way to the doctor and would you please call an ambulance? And they called an ambulance and you know she wasn’t reluctant to go with them. She must have known that something was not really right...” (p 24)*

Rebecca eventually found a medication that worked while voluntarily hospitalized for research participation. However, her mother was concerned over her weight gain and became involved with trying to help her lose weight. She was hard pressed to think of why Rebecca would not be more concerned for her own weight:

Maureen: *“Well I think [her self-image] is better. It’s more normal but the fact that she’s gained all this weight has not helped and you know, even though I remind her, I try to help her in a kind of gentle way to remember that she’s eating too much for her size and that’s why she’s gaining weight...[She’s] not worried as much as I would have expected...but I don’t worry, I don’t want to upset the apple cart, so I don’t worry too much about it. But I do say, you know, don’t forget to get on the treadmill today, but I don’t think she stays on there very long. The more weight she gains, the harder it’s going to be to lose this weight and I try to tell her that, you know.”* (p 29)

Sometimes she changes from a gentle approach to one that is blunter:

Maureen: *“I tried to be a little bit more aggressive about it. I remember last week, I tried to, I said you know I really don’t think you’re spending enough time on the treadmill to make it, you know, you should get up and get right at it and at least stay 45 minutes. And she made me know she didn’t want me interfering or what did she call it, getting involved with her workouts...I said, I’ll back off you know I’ll back off...but every now and then I do ask I said did you get on the treadmill today? Did you do any walking?”* (p 31)

Richard worked tirelessly to keep his daughter out of the hospital when she became ill, which he was ultimately successful in doing.

Richard: *“I think somebody spiked her drink or something on that trip, I think they did, you know, and because I think she just had a nervous breakdown and then I didn’t want her to go into the hospital, I was doing everything I could to keep her out of the hospital. I’m still doing that, because it’s not a place for anybody, you know.”* (p 15)

He and his son took shifts in watching Alison while she was ill. He also created his own homemade version of occupational therapy, sending Alison to a pottery class. Although his hospital experiences were scary, he commented that he enjoyed occupational therapy projects, which was his impetus for creating such an experience for his daughter:

Richard: *“So I took off....I was taking off every day by twelve noon and going home and watching her and [her brother] would be watching her in the morning from the time that she woke up until he went....he would ride his bike up to [location] from where I lived in [location], when he was living with us. And he would watch her in the morning, and then I would watch her in the afternoons, so we had somebody with her. And then also she went to her occupational therapy class in [college location] and did pinch pots you know, she did that every day. She went on the bus to get there. She might have told you about that.”* (p 16)

***Practical Support Roles.*** Practical ways of family support of their young adult children included assistance with finances, materials, housing, or other resources for living. After Sean decided to accept treatment, Paul was able to put his past mental health skills to use in helping his son finish his social security application process so that he was able to gain a financial security net and healthcare:

Paul: *“Well it just seemed like, well I come to a point in my life, where it’s like people can overcome stuff, and sometimes in order to overcome it, you’re going to need some assistance. So I was there to assist him. I’m a human service worker and I’ve been a case manager and direct care for individuals for twenty something years...I had no idea. I had no idea that even my attitude toward individuals with mental health issues had changed. My mind set as it is today, isn’t as it was then. It was just a job. It was just a job.” (p 16)*

In addition to roles around managing illness, Paul is committed to helping his son meet his goals of further independence. He supported Sean in finding his first place, a room of his own in a house with a couple of roommates. When Sean was ready to move into his own apartment, Paul supported him through this process financially and emotionally. He was instrumental in getting furniture for Sean’s new place, and paid his first month’s rent and security deposit. Another important goal that Sean had for himself is to get his driver’s license. Paul explained his role in helping his son to meet this goal:

Paul: *“So, I told him, you know, that’s what we were working on his driver license thing, you know. He took the test, I think four times, before he passed it, you know. He was just so nervous in taking that driver’s test, you know. But now he has an official driver’s license, so we got to get him an official automobile he can drive. So that’s a good thing.” (p 26)*

During the follow up interview, Paul happily reported that Sean was able to get a “hooptie” car!

Maureen highlighted her experience of being involved to a great extent with Rebecca, who was the oldest of her three children. She explains how it seemed necessary to be absorbed with her as she required much in the way of constant support:

*Maureen: "Actually it might have been in high school and you know we just couldn't understand why we gave her what she said she needed at the time. She needed a car, we enabled her to get a car and apartment and helped her do this and that and she finished school with no debt and we paid for her entire college education. And you know things seemed to, you know she got jobs and seemed to do well in them, but you know there seemed to be complications always. Always some stressor, always some you know difficulties. She was a stressor for me, let me say." (p 3)*

As Rebecca's illness gradually progressed, she and her husband were both called on to help their daughter through bizarre and scary situations:

*Maureen: "She would stay at her condo on her own pretty much, and you know she was locking herself out, she'd call in the middle of the night that she locked herself out, and could we come and open up the place for her. I'd find a card from the guard desk at the cathedral across the street in the middle of the night, I mean she would disappear sometimes and we wouldn't know where she was and she wouldn't call in and she had a cell phone, she'd lose her cell phone, we've been through about four or five cells...she'd call me from [the city] saying um, I spent all of my money and I can't get back, and can you come and get me?" (p 21-22)*

After a crisis situation where she felt Rebecca was becoming a danger to herself, Maureen reacted by setting a firm limit for her to come live with her in order to keep her safe:

*Maureen: "We said this is it, you're coming home. No. Okay, you're not going to stay here anymore so that's when we brought her home and said that's it. I say to myself, well I'm just going to have to work to get this right, you know, because she's a danger to herself even though they wouldn't say that in the hospital...I have to approach this like every other project I approach and you know get her into the, into the right doctors and the right situation..." (p 22)*

Richard supported Alison financially in the past, using up his retirement money to keep her afloat:

Richard: *“But she gained a lot of weight and she wasn’t getting any dates and she’d tell me I haven’t had a date for years and all of this. It was just pitiful, I felt kind of bad, and I was paying for [inaudible], and that was like \$800 a month. Well that was \$450 that that with the gas and cigarettes and I was keeping her up in, and it was like I was paying like \$900 a month for her, you know, and that was what was left of my 401(k) and she....she was doing volunteer work all this time or she was teaching Vietnamese people how to read and so forth, and then she got a volunteer job at the library, and then thankfully, right before I was going to have to sell my house, because I didn’t have any more savings, and I can’t own a house with no savings in the bank, you know, in case of, you know, emergency or whatever might come about. I was about to have to sell my house and she got the job with they cut and print charges cards so thank god, you know, and she loves that job. She’ll complain about it, but she really loves it.” (p 31)*

### **Stepping back.**

Parents described various experiences of feeling the need or feeling forced to step back from their loved one. This experience was distinct for each family. Sheila has played the game of figuring out when she is permitted to be close, and when she should back away from Dan’s life:

Sheila: *“He doesn’t tell me if he’s having particular problems. He just tries to deal with his therapist. Dan filled out the [social security application] papers himself. It was his decision. He made the appointments, he got his job at [grocery store] that he’s doing now on his own. He’s just taking charge and taking over and sometimes it’s very difficult because I want to ask him things like you would anybody...he gets very upset if I try to be, I don’t know, I guess what I’m being is caring and interested and yet he doesn’t even allow me a little bit of space that way. He’ll say ‘oh, mom... I’ll talk to my therapist about that.’” (p 13)*

Dan has kept most of his medication information private from his mother, including most side effects:

Sheila: *“He shared to me that he does have side effects but he won’t tell me what they are. He won’t discuss that with me. And some of them may be sexual and feels privately about it or things like that. From the very beginning he’s been very private about it, so I don’t know really what he’s been dealing with that way. I know that he’s had trouble with blood pressure with some of them and I know that he has had a lot of trouble with arthritis which is probably another side effect...” (p 19)*

It has left her second-guessing herself when she interacts with Dan:

Sheila: *“And it boils down to the microcosm which is ‘Dan do you want to come over to dinner tonight?’ Every time I say that I think oh my gosh, I’ve overstepped my number of visits. You know, I shouldn’t be inviting him to come to dinner more than once a week because you know that’s just one of those things where now I’m in a different role where I’m not worried about am I imposing myself too much on him. If I say ‘oh, let’s take a hike somewhere.’ Then I think to myself, now am I a problem to him because he thinks that he needs to entertain me?” (p 32)*

Sheila commends Dan on his ability to care for himself, and even reported that she felt relieved by his abilities. However, she wonders if he is carrying too much burden alone:

Sheila: *“I mean he has so much ability to take care of himself that I shouldn’t worry about him so much. But I always thought that I needed to help him and probably it was because I didn’t want him to feel like this tremendous burden was only on him...” (p 14)*

Before the advent of Sean’s homelessness, Paul was involved and allowing Sean to live with him. Paul was preparing to re-marry. However, Sean’s illness caused him to become hostile and blame others in the household for his problems. This contributed to their impending separation:

Paul: *“I think that my current wife and I were just getting ready to get married and I had Sean living with us and he just had this sense of entitlement that was like, you know, ‘yeah, I’m here and no I ain’t got nothing to contribute to the household’ you know. He was sick, and America, the planet, everybody was against him in his mind, and that’s when he was like ‘I’m leaving. I said ‘where you going?’ ‘I’m going to Canada.’ And he went!” (p 19)*

Before Maureen grasped the severity of her daughter’s progressing spiral of mental illness, she was desperate for separation. Though her husband was hesitant about Rebecca going to college, Maureen encouraged it, hoping this would relieve the pressure and that she would eventually learn skills to be independent:

Maureen: *“When Rebecca lived in the house like my blood pressure went up you know. It seemed to come back down and I just got calm again and when she wanted to go away for college, I mean my husband was saying ‘oh, she’s not ready to go away. I don’t think she can manage things by herself.’ And I was thinking to myself, oh I think she needs this. I think she needs to go away. It would be the best thing for her and for us. She needs to be able to handle things on her own...I said ‘let her go!’” (p 3)*

Maureen's frustration grew to the point where she felt forced to create emotional distance from her daughter:

Maureen: *"I eventually got to the point where I said, well, this child is someone I don't think I can ever satisfy. So I just kind of pulled back and said you know she's going to have to do some things on her own and figure her way out of this, that and the other. You know, like the other [children] ...So you know I had created a space."* (p 4)

While Maureen and her husband became more involved with Rebecca during crises and episodes of medication non-adherence, Maureen felt the need to know more about her illness by finding a doctor that knew the family to help their daughter. She became aware through her daughter's resistance, that this option was no longer on the table as Rebecca sought other care:

Maureen: *"I don't think she was particularly pleased. In fact, she wanted to go back to [the previous psychiatrist] because then she could see somebody who would, nobody else was poking and no one else in the family would be involved then. She wanted to be, she wanted that kind of power herself..."* (p 17)

Richard's experience was again divergent from other family members in this study as he struggled to manage his own illness. He did, however, make a comment about Alison's personality and her comfort with letting her emotions flow freely with her father:

Richard: *"Well I would just say, I don't know how, I mean how do I say this? See, Alison is kind of immature in many ways. Her reactions to things, she works in a library, she has people, every stripe coming in there of the public, dealing with the public very easily, but then she'll just kind of fly off the handle about something, you know, and she's got to try to get that under control. She saves her best tantrums for me, I think [CHUCKLING]."* (p 26)

### **Guilt and Isolation.**

Each family member in this study described their struggle with guilt, isolation, or both to varying degrees as they tried to support their adult children. Some families dealt

with their own significant issues, such as alcoholism or mental illness. Others carry remorse over divorce or unstable parenting situations. As Paul reflects on the separation between he and his son when he became homeless, his guilt is overwhelming:

Paul: *"[I wasn't there] as much as I wanted to be or should have been...Oh, it hurts. Nobody wants to like, you know, appear to abandon their child."* (p. 18)

*"I feel guilty...well, maybe if I wasn't drinking I would have noticed it sooner, or maybe if I'd been paying attention when he was younger, this could have been addressed earlier, you know. Maybe I could have been a better father. I don't know, but you do feel like you did have something to do with it, you know, you do."* (p. 42)

Although Paul was born and raised in another state, he came to his current location at the suggestion of his sister, who knew of Paul's struggle with alcoholism and a nasty divorce, desiring a "fresh start" for her brother. He is glad that he made that decision, although alcoholism continued to have a strong hold in his life for years after he moved. He believes that this had an impact on Sean:

Paul: *"I guess my age around 36 is when I went into treatment for myself. Yeah and that didn't take at that time. Geographical cures don't work, it wasn't the location, it was the person in the location; that was me. And so Sean came back to [this state]...he was back and forth, back and forth...I hold myself responsible sometimes, because it's not easy to hide alcoholism...he saw me as being too bossy, you know, you can't tell me what to do. And he's getting bigger...it was back and forth, him and me, and his mom and him."* (p. 8)

Paul explained the spiteful relationship that he and Sean's biological mother shared after their separation, making it especially difficult to parent from afar when Sean lived with his mother:

Paul: *"We didn't like each other, and it wasn't good...the messages that were left on the phone and on the voice mail. Oh man, it was amazing...My ex, she never did tell me [about Sean's illness]. It's like when he got locked up I had no idea he was locked up, you know until after he was released from jail, you know; a serious lack of communication...if we attempted to communicate, it'd start of normal and then it just went to, 'and I'll tell you another thing, and about your momma!'"* (p. 9)

Sheila has been the primary support for Dan, since her and Dan's father divorced. Dan's father soon re-married to a woman with two sons. She feels that the divorce and transition to a new family was not only challenging to her, but a significant traumatic event in her boys' lives:

*Sheila: "I think [the divorce] was a horrible thing for Dan and [his brother] to have that happen to their lives. [His brother] went to the university not too long after that, but Dan went through a terrible situation where he was between two households and trying to please his father." (p 15)*

As for Sheila's new husband, whom she met while in the Peace Corps in another country, he is "just as difficult" as her first husband:

*Sheila: "If it were me and I was Dan, it'd be just torture to be around that man. He has the most wonderful heart...but he never talks and if you have someone around who is paranoid and he never talked to him, it just builds up mountains of problems...There's not only the language barrier, but there's a lot of other issues..I think Dan wanted to have a relationship [with my husband] and not able to, it makes Dan feel I think even more self-conscious and lacking in himself that he can't have a relationship with this man. It's so difficult. Oh Lord!" (p 17)*

During Sheila's follow-up telephone interview, she was asked if she thought there was an ideal family relationship that would help her son most at this point in his life. She identified the importance of sharing profound problems amongst family members and to feel that one is accepted for who they are in the family system. She is learning more about this now in her life, as she recalled a recent trip to the beach with Dan and his stepfather. Her husband showed concern for Dan as he stepped into the ocean water, wondering if he knew how strong the water currents were. This pleased Sheila to know that her husband would show his care, and she hoped that Dan would be able to pick up on these intermittent gestures.

Maureen commented on the isolating experience of learning about the illness on her own and preparing herself for educating her family:

Maureen: *“No one else was going to get the books. No one else was going to the psychologist. No one else was trying to find a psychiatrist, and I just felt alone. This is part of my role as a mother, you know, I’ve got to get us through it, you know...[My husband], he was a little bit on autopilot. I mean he’s a little bit, you know it’s hard to break habits.” (p 14-15)*

Maureen admitted that it is sometimes difficult to balance her roles as a mother in this situation, and that she now relies on her own intuition:

Maureen: *“It’s difficult, but I’ve gotten to the point where I go with my gut [laughing]. I mean that just, it’s sort of like, you know when I had Rebecca the first time, I got all the books that I, you know, child development and that kind of thing and I was reading all the time...The third one came and I said, I pushed all the books in the corner, I said ‘okay, I’m going to wing it [laughing]!...I’ve gotten to the point where I know that all these professional people don’t have all the answers, okay? And I’ve discovered that the hard way, and I said well, if they don’t have the answers, you know, I can read the books and get some guidance, but the bottom line is, what matters is what I’m going to do to take care of this...so yeah, it’s hard to know when not to get involved and when to get involved but I just kind of feel like I’ve got a better sense of it now.”(p 30)*

Sheila has taken on the bulk of responsibility for Dan during the course of his illness. Recently, her other son has evolved his brotherly role to include telephone support to Dan. She is happy to have someone else helping Dan as she does not feel as isolated. She reflects here on why she did not ask for help earlier:

Sheila: *“Well, it’s interesting when this happened was about the time that [Dan’s brother] went away to college and so the day to day impact was really mine. And I felt like I was probably protecting [his brother] a little bit, thinking that he should have some time on his own. Plus, he’s physically disabled...So he’s had a lot on his plate and I guess I really did assume more responsibility than was necessary but I was here and he wasn’t. So I dealt with it.” (p 2)*

She also points out that she eventually learned to re-focus energy on herself, an obvious process that occurred over time:

Sheila: *“It’s taken a long time to know that I deserve some attention for myself.”*  
(verification call)

Richard reflected on his unanswered prayers about his children getting mental illness as he and their mother lived with:

Richard: *“I pray, hope and pray. When I came up here, when we first came to [location], I hoped and prayed that we would end the cycle at time, you know. But as it was, it affected my children too, so. (p 22)*

He has not given up on praying for his potential future grandchild:

Richard: *“You know, Susan, if we ever do have a grandchild, I hope we can break this cycle of poverty of spirit or whatever that’s inflicted us, you know.” (p 17)*

### **Culture and family ways of life.**

Cultural experiences emerged as an interesting sub-theme as families discussed the ways in which they dance in and out of their adult children’s lives. This viewpoint could stem from generations before them and could be affected by ethnicity and family customs. It could also include pervasive experience in the culture of mental illness.

Maureen spent time reflecting on her African-American heritage, particularly the ideals of her parents and experiences with family mental illness.

Maureen: *“I was brought up in a family where even though my father was in medicine; he was a dentist. My mother was well-educated, she was a school principal. They were of the generation, first of all they were old enough to be my grandparents because I was born when she was forty-eight and my father was fifty-something. And so that generation, particularly African-American families did not subscribe to the use of psychiatrists very readily, okay? It was always, okay if you’re going to see a psychiatrist make sure you don’t use your insurance because it’s going to show up on your record and it’s going to mess you up, okay.” (p 6)*

When Maureen was confronted with the seriousness of her daughter’s illness, she explains how she integrated the standards of her upbringing to make sense of what was happening:

Maureen: *“I just wanted things [with Rebecca] to progress in a logical form, you know. We had been successful, we had fairly successful kids, and you know if one of them got sick you take them to the doctor, you get a pill or two or you know a therapy or two, they get okay and they move on...I was expecting [this] to happen with Rebecca. You know, thinking about, thinking kind of back with my experience with my mother who had said, who always seemed to be of the mind, you know ‘something’s wrong, you fix it and you move on’ okay? And nothing’s really wrong [LAUGH]! Nothing’s really, really wrong.” (p 8)*

As a result of growing up amidst the chaos of mental illness, Maureen explained that she chose a profession that was not focused on listening to peoples’ problems:

Maureen: *“Well, I’m glad you enjoy listening to me, but when I was in college, we was trying to decide on our major and I said, I don’t want to listen to anybody’s problems. So I do not want to be a psychologist [laughing]! I said, you know, after having grown up in a way I was very protected. But as I told you, I grew up with a person who actually had a series of mental illness and after that you know, I come to understand how I chose my major by process of elimination, you know. I didn’t want to be bothered with anybody else’s problems...” (p 41)*

At one point in time before he was diagnosed, Sean lived with his grandmother, mother, and aunt. Paul recalls that Sean was influenced by each of them to believe that his illness was not severe. Notably, Sean’s grandmother lived with schizophrenia:

Paul: *“I think they shared information, but [his grandmother] tried to minimize his illness. That’s when she’d collect these seeds, and she’d say he don’t have no problem, he just got a problem with social anxiety and he’s just nervous around. No, it’s a little more than that, but I think he was feeding into that...he was there with her in that environment, you know.” (p 12)*

*“Oh, it’s just again, here again we go back to that stigma, my son ain’t sick, you know. I think [Sean’s mother] is more concerned about you know how it’s going to make her look. Your son’s on this medication, something must be wrong with him. Therefore, something must be wrong with you too.” (p 42).*

Dan started to seek treatment when he was about 11 or 12 years old, stating that he felt there was “something wrong with his brain.” His parents thought at the time that it was a typical adjustment problem caused by the stress of the divorce, so his treatment

did not start until his symptoms became more intense. When asked what his father's reaction was to Dan's illness, Sheila explained:

*Sheila: "His father has been in denial most of the time. His father's brother had schizophrenia and committed suicide. His mother's two sisters have been institutionalized all of their lives. [His father's] family is very uniquely intellectual and mentally very unique and I think that he did not want to admit that there was anything more unusual for Dan than just what he had grown up with, it was an unusual family." (p 15)*

Sheila said that one gesture that Dan's father made is to take a mental health leave of absence when Dan became ill, and took him into his home for a month. This surprised her, but unfortunately the situation did not end well:

*Sheila: "[His father] demanded that Dan get better, that he'd had enough time now and that he needed to get better...ever since then right, you know a period of time after that, he moved out of the town we lived in, moved [across the country] and had very little to do with Dan except for conversations on the telephone...Dan wrote this book and he totally withdrew from Dan because he wrote a book about the family situation and then so, for them, from my perspective, it's been up and down. Dan is not allowed to mention my name around his father...So it's not something that the two of us could work out together and support Dan at all." (p 16)*

Richard reflected back on his parents' reaction to mental illness. He was the only child in their family to have developed mental illness. His father did not understand mental illness:

*Richard: "They didn't understand. They didn't understand it. No, they didn't understand it at all. My dad had been in the claims business and he used to....he called it a traumatic neurosis, and he would never grant the claim for somebody who was claiming a traumatic neurosis. He thought they were malingering you know. Because my dad was self-made, completely went to work when he was thirteen. (p 23)*

*"Sometimes I think maybe that's what we're still living down. That was the only thing, I don't think he was totally fair on these claims about, because he used to always say, if they came to him first to claim it, in an insurance case, you know, whether it be automobile, workman's comp., homeowners, whatever, they would never go to a lawyer, because he would be so fair and honest with him, but that's one thing he could not see was mental illness. He could not believe that." (p 24)*

The culture of mental illness has been weaved into Richard's adult life. His experiences have helped to shape his parenting style and outlook on life:

Richard: *"I do, I like to encourage them because I've been through a lot and I just....it's like my dad used to tell me when I wasn't doing too well because I had problems from the time I was a child, he used to say, just have faith, you know. I was in college and I thought I knew everything, he didn't say to have faith in God, he just said, have faith. So I always had faith that something was going to work out for the better, you know. So now it seems to be, thank God."* (p 8)

### **The Abyss of Family-Provider Discourse**

Providers could potentially be viewed as the "support for the supporter" when a relative is ill. However, families indicated that overall, their interactions with providers were lacking.

#### **Exclusion from consumers' health care.**

Three out of four parents would have liked to have been more involved with the consumer's healthcare. Again, Richard is the exception in this case as he would prefer to have little contact with providers. Maureen explained her perception of meeting with one of Rebecca's doctors who finally welcomed their input:

Maureen: *"She brought us all in to talk together and seems to be that was the most intelligent thing any of them had ever done. I mean, sorry [chuckling]. I mean just why not involve her family, she's not getting anywhere on her own. She's just getting worse...she needed medication and the best place she had found is for someone to be in a residential facility because compliance to medication there was not really good. That's what she was trying to tell us that I was beginning to understand because she had been with this other doctor and she'd been given Risperdal and some other stuff. She'd take it for awhile, and then she'd stop."* (p 16)

For some time, Rebecca would not give permission to her parents to be involved in any part of her treatment with her psychiatrist. At one point, Maureen expressed her desire to be involved with one of Rebecca's past doctors:

Maureen: *“Yeah, I mean for instance with Dr. [name], I said you know sometimes I would say ‘I think you need to have us come and talk with you as well’ and he said ‘well, with Rebecca’s permission we can do that’... And then, we’d go talk to him and you know tell him about things that had happened because you know, it didn’t seem like we were getting anywhere or she was improving. And I said ‘did you know this that and the other?’ He said, ‘Oh, no, Rebecca is not very open with me. I need to hear these things so that you know, I can know more.’ I said to myself ‘well gee, why didn’t you invite us to give you a little feedback? I mean, we’re living with her every day! How do you expect to make any progress if you think she’s being, what’s the word, evasive, okay?’ I don’t know, to me Dr. [name] was the most professional of all I think probably and Dr. [name] because they brought us in and knew that they needed to bring us in, okay... Why the others just took our money and drug us along...I just don’t get it.” (p 36)*

This disconnection has impacted Maureen’s ability to know how to support her daughter in work endeavors:

Maureen: *“Yeah, they’re not telling me anything. Well, I don’t know. When we were trying to get her to see if she wanted to come in every day, she said ‘they said I shouldn’t come in every day.’ And so I said ‘well, how often? Maybe two days a week?’ And she’s like ‘yes.’ I don’t know if she’s clear about what she should be doing.” (p 38)*

Furthermore, Maureen felt scrutinized during a meeting with hospital staff as they prepared Rebecca for discharge:

Maureen: *“When we left [the hospital] and they had the final discharge meeting with all the nurses and doctors and stuff like that, you know they asked me to speak about stuff, and I mentioned [the side effect of disturbed menstruation cycle] and then the case worker got angry at me later for mentioning it...I was bringing up things that you know were obviously a result of her being psychotic, you know, as to how she was handling things at her condo...the social case worker was acting like I was embarrassing her in front of all the staff. I said well, what are we meeting to, I mean weren’t we supposed to discuss, I mean all I wanted to know is what’s the next step in recovery, I mean how can you find out where we’re going unless you know where we’ve been? But I don’t know...They’re not family supportive. All this HIPAA stuff is not to the patient’s best interest, because you know, they can’t make it on their own, they need assistance. They need a support system. If we weren’t here, Rebecca would be living down on the street, I’m sure of that.” (p 35)*

Paul also felt strongly that family members who see their relative on a regular basis should be included in, at the least, the diagnostic process. He reflected on lost time in Sean’s life as a result of misdiagnosis:

Paul: *“Yeah, they should involve, just as we are having this conversation now, providers should have the same type of conversation with family members, because when he was initially diagnosed in [location], he was going to [treatment location]...and I spoke to his therapist on the phone and she just, during the course of the conversation, she said, well, gosh one of the things that happens with social anxiety. He was self-reporting and she didn't do any type of investigation! So, she was treating him for social anxiety and then I had to tell her, I said he has a diagnosis of schizophrenia. What? Yeah, you know. So, like I think it's important that you get involved with folks that's been living around this person the person that's been diagnosed, and get some input from them and let you know what they saw, you know, because the client's not going....oh, I don't have any.....I've got a cold. I've got a really bad cold.” (p 46)*

Sheila's experience with providers for Dan's care left her feeling excluded when providers advised her to step back:

Sheila: *“This is the other thing that's been so difficult is at a certain point, they told me to back off, and it wasn't said any kindlier than that. But it was meant that Dan needed to be more independent...” (p 13)*

On the other hand, Richard did not have any family-provider interactions to report because he worked so feverishly to protect his daughter from the healthcare system. He did, however, have his own impressions of healthcare providers based on his previous hospitalizations:

Richard: *“I mean [psychiatrists], all they see in you is money...And when they come in, they don't tell you the right things, they don't help you. They just look at you, you know...They just never seemed to, I mean even at that time I was thinking why don't you try to reassure me, you know, when you come in and see me? Instead they would come in with aides on either side and some kind of show of strength. I'd say well I'd like to speak with you in private, you know. They never would and just kind of confrontational you know.” (p 17)*

### **Disappointing responses from providers.**

Family members brought forth various challenges in trying to get help for their children from providers. The issues varied across cases and many problems centered on direct or indirect medication management. Examples of issues that received disappointing responses from providers include difficulties around doctors withholding

the full picture of side effects, discrepancies in recommendations for alcohol consumption, the frustrating diagnostic process that often involves medication trials, access to healthcare, and/or questionable decisions regarding treatment that may have led to adverse consequences for the consumer and family. When her daughter dealt with the terribly unwanted side effect of abnormal menstruation on Risperdal, Maureen asked the doctor for help:

Maureen: *“And then I didn’t realize it, but there’s something in that medication that interferes with your ovulation and your hormones and this, that and the other. And it would have been nice if the doctors had told us that. And I mentioned it to the doctor and he said ‘oh, that’s temporary you know, when you get ready to have children you know we take you off of it for awhile, you can terminate the medicine.’ But Rebecca didn’t want to believe that. And even in the back of my mind, I said to myself damn, you’re married, you’re getting ready to have children and they’re going to take you off of psychotic medication? That does not make sense. What do you do then? They put you on something else? What do you do? So that didn’t leave us, so she didn’t want to take it because of that...” (p 20)*

Maureen felt that doctors lacked clarity regarding regulation of alcohol consumption while taking antipsychotic medication:

Maureen: *“I was wondering myself, and so I asked the doctor, and he said it’s okay to have you know, a glass of wine with a meal while you’re taking this Risperdal. Well, Rebecca kind of took that to the bank you know? It wasn’t a glass of wine, it was like sometimes more like two or three and you know more than just with her meal you know? I’d come in and she was drinking wine, and I could tell that was increasing the symptoms, you know and I asked the doctor again, and he’d say the same thing...and you know the people at [the research hospital] said, ‘oh, by no means should you have alcohol with Risperdal.’ And I said how can there be so much discrepancy among the opinions of these professional people...” (p 20-21)*

Maureen also experienced a surprising occurrence where the doctor would not write her daughter a prescription for Risperdal. This left Maureen to wonder how severe her daughter’s illness could be if they doctor would not prescribe medication:

Maureen: *“The doctor didn’t have her on any medication because she had, after interviewing Rebecca, she said Rebecca is not going to take this medication. There’s no*

*need for me to prescribe it. So you know, because she was totally anti-medication at that point, I said okay, well, I guess she's not that bad. Once she gets to the research hospital, we'll figure out what she needs...But she got progressively worse..." (p 23)*

Sheila recalled Dan's illness progression, beginning with trials of anti-depressant medication but needing to move toward anti-psychotic medications as his schizophrenia/schizoaffective diagnosis became more apparent. She pointed out the way in which medications were used as trials in the diagnostic and treatment process for her son:

*Sheila: "Afterward [the doctors] realized that it was probably schizophrenia and tried several different kinds of medications and tried to get him stabilized for the month that he was there. Again, it's just practice, let's try this one, let's try that one, let's see what this one does, let's see what that one does and all of them having the side effects and reaching some point where they thought that he was stabilized..." (p 11)*

At one point in his illness, about the time that he graduated from college and seemed to have grandiose plans, Sheila recalls that Dan sought out a medication change which she perceives, in part, led to his full-blown relapse:

*Sheila: "He was feeling so good that he wanted his medication changed and he went to his doctor and said he wanted it changed and the doctor said 'no, I don't know you well enough so we'll wait awhile.' And then he got laid off from his work so he was going to a clinic and a nurse practitioner took him off his medicine. She didn't take him off one, she took him off all of them and that seemed to be the end of this tremendous crash that he went through. After that, he went back to his old doctor to get back on the old medicine, and the old doctor didn't have time, and the other doctors didn't have any room for him because he didn't have insurance and he's just been through hell trying to catch up where he was before. And you know that's just an overview..." (p 12)*

After searching for someone to help him, Dan placed ultimate confidence in a provider to change his medication. Sheila feels the provider did her son a disservice, though she can understand why Dan placed his trust in her:

Sheila: *“He’d been so patient trying to get somebody to help him with his medications, that when she said ‘let’s change this and see how it goes.’ He thought well, she knows what she’s doing and of course, she didn’t.”* (p 25)

*“I felt that he thought she was knowledgeable because she, you’re right, she did listen to him and she was willing to make some changes, which no one else was. I think that was wrong, but that’s probably why he wanted to follow her orders but also why he felt good about talking to her because she was willing to make some changes.”* (p 27)

One of the most bothersome aspects that Sheila sees as part of Dan’s utilization of mental health care is the disconnection and lack of communication amongst providers involved in his care:

Sheila: *“Well, this is another one of those big problems with psychiatry now is the person who gives him his medication is not the person who does his therapy, which is the most ridiculous thing in the whole world. I mean, you have to be stupid to think that made any sense! Because obviously the person that he’s talking to is the one who knows how he’s doing with his medication, what his symptoms are, what his side effects are. He goes into the psychiatrist, it takes 8 minutes for the doctor to say, how you doing and then what’s Dan going to do, take any hour to tell him how he’s doing? He’s going to say ‘I’m okay’ and then he fills out the prescription...”* (p 20)

She further explains her frustration, bringing forth examples of providers who pay lip service to client-centered care:

Sheila: *“Oh, they don’t [communicate] ...it would be really nice if the therapist and the person giving the prescription would communicate with each other, but never to my knowledge does that ever happen. Even though you ask for it to happen, and at one time we went to a doctor when I was helping Dan more and stated that we wanted that to happen, that that was very important. ‘Oh, yes, [Dan’s] part of the practice.” Never happens. It’s totally incompetent care as far as I’m concerned. It’s not scientific. You can call a million doctors and they’ll all tell you that you can pay \$150 to come see me in my private practice because I don’t take insurance anymore. I don’t deal with those kinds of inconveniences...”* (p 20)

In addition to their echoing experiences of poor or absent communication with providers, Sheila and Paul were in touch with the difficulties they observed in their children’s brief interactions with prescribers:

Sheila: *“He now sees a psychiatrist through [treatment location] for you know, 5 minutes. And I know that because he’ll say ‘oh I have to see the psychiatrist, will you drop me off?’ So I’ll say, ‘should I wait?’ He says, ‘oh, yeah, it won’t be more than 5 minutes’...that’s right, don’t worry about a parking spot mom!”* (p 28)

Paul: *“I think he really likes his therapist, I don’t know what type of relationship you can form with the psychiatrist that only sees him like once a month or twice a month even though and you’re just number thirteen on the list of twenty. All right send him in, and get him out of the way and send in the next one. You know, that’s the nature of the beast, you know. So I don’t know how strong that relationship is with the psychiatrist.”* (p 26)

Another significant experience that not all family members discussed was access to quality mental health care. Sheila was the main family participant to bring this issue to the forefront:

Sheila: *“Well, in the beginning when Dan was at the university, he had health insurance; he was covered as a student. And then when he stopped at the university when he graduated, he didn’t have health insurance anymore so the doctors who he was seeing couldn’t see him unless he paid cash out of pocket, which we really weren’t in a position to do. So I must have called oh 25 or 30 doctors to try to find out if there was some way we could work out a financial relationship and they said ‘no, it’s just cash up front and we don’t take any kind of insurance.’”* (p 28)

She went on to express her thoughts on health insurance more in depth as related to fragmented continuity of care:

Sheila: *“Part of that I think is a response to the doctors against insurance companies and the way they manipulate the payment system, but the patients are the ones suffering...these alliances [with providers] changed more frequently than they needed to because of these changes in his economic situation. When he was working and had insurance, it would be one doctor. When he wasn’t working and had no insurance, it’d be another doctor, and then when he completely went on SSDI then he was in another...”* (p 28)

### **Positive experiences.**

Though families presented many significant challenges of working with providers, they also provided affirmative examples of the presence of quality health care. Richard, who typically did not have many optimistic views of providers, commented on his appreciation of guidance received from treatment providers:

Richard: *“That’s the first thing that the psychiatrist will tell you that is good advice. They tell you just worry about yourself, you’re not going to change them, you know?”* (p 26)

In all of Dan’s many interactions with providers, Sheila perceives only one practice to be of excellent caliber and to this day, she remembers this experience fondly:

Sheila: *“When [Dan] was out at [treatment location], the therapist and the psychiatrist and of course, the residents there and the team were involved on all levels of his care from therapy sessions all the way through...I felt that the care was excellent, and afterwards he went back to see the psychiatrist and to get therapy there for a period of time and that was the best. I felt the most confidence in that group. I felt like they really were doing a good job...”* (p 20)

*“They said ‘well, [this side effect] is something that you shouldn’t have to deal with on top of other things. Let’s see if there isn’t something that would work better. That kind of consultation was very helpful for him in that one setting...”* (p 27)

In addition to effective communication among providers, one of the keys that she saw to quality “scientific” care is the tracking of Dan’s response to medication:

Sheila: *“I think that was the key that the therapist and psychiatrist were communicating and I thought the way they handled trying different drugs and the track that they kept of things that were going on was very beneficial to Dan...by keeping track of his response to medication. You felt like they were learning something from if they tried risperidone and he had symptoms come out of it, you felt like they were watching that and they were listening to what he said about it and how he felt, and I just felt like it was science-based medicine...”* (p 21)

Even though this experience was approximately 15 years ago for Dan, he has not forgotten:

Sheila: *“I really feel myself that that was very beneficial and Dan still speaks fondly of his therapist there and his doctor there and how smart his doctor was.”* (p 21)

When Rebecca was finally admitted to the research hospital, Maureen noted some positive experiences with providers:

Maureen: *“I could tell that she wasn’t on the medication hardly at all when she got [to the research hospital] because she was having all these symptoms. These little paranoid things about, she had developed a paranoia against black people, particularly with dark*

*skin...I had to explain to her [African-American] nurse that my child is not anti-anything okay. This is part of the illness, okay, and they realized that I think...Yeah, and I said oh gosh, are we ever going to get any help with this? But they were calm and very professional you know...to my surprise Rebecca decided to stay and one she decided I said [to my husband], 'we need to get out of here quick! [LAUGH] Let them do their job!'" (p 27)*

### **Advice to providers.**

Participants were asked whether they would have any advice for providers to better care around medication and illness management for their adult children. They each offered rich perspectives as they reflected on their experiences thus far. Richard explained how psychiatrists should have reassured him when he experienced paranoia about his medications being horse manure:

*Richard: "Yeah, in other words selling you, now if you take this medicine, you know it's going to help you. It's this good medicine. Instead they don't tell you anything. So you say I'm not going to take it, see I wasn't taking it. I thought it was going to harm me, they could tell you 'no, this medicine's going to help you. We know this because we have your situation, your care uppermost in our thoughts, you know and we really care about you.' I never found one to come in and want to talk to you. I had this one woman who last time I was in there, she'd come in as Doctor, what was her name, Indian woman, she said, 'now look at you, you're a lawyer, you know, what is all of this' or something like that, you know, it was kind of berated me her saying that. "(p 18)*

He further explained how a doctor could encourage and explain rather than demoralize:

*Richard: "Yeah like I say these doctors in the hospital can tell people that this is good, this is going to help you, you know, take it. This is medicine, it's not horse manure, you know. A little bit rather than to come in and just kind of, you know, looking at you or berating you by saying oh, now you're a lawyer, what is this, you look like [INAUDIBLE] you know." (p 32)*

Sheila shared her thoughts on how families could be part of the communication with doctors, therapists, and the consumer:

*Sheila: "I think communication would help even though his therapist or his psychiatrist says you know, be independent, make these choices yourself, do what you need to do by yourself on your own, break this tie with your mother. We could be objective about a meeting to discuss what medicines are and what they do and then I could stick my nose right out of it until there's a change and then they could say 'well, we're making this*

*change.’ Because I think being alone with such a profound illness and medication choices and decisions is a horrible burden for one person, especially when they may not know if they’re making a good decision because they have a brain disease.” (p 32)*

Paul encourages providers to take advantage of a consumers’ moment of clarity:

*Paul: “I think medication non-compliance is a major issue when you’re treating individuals for mental health issues. I don’t know of any advice or suggestions I could make to a provider that would change that. I guess you would have to just like emphasize and reemphasize that individual’s moment of clarity, you are at a place right now that you realize that you have health issues, mental health issues, and in order to make that better, this medication may do that for you, and I don’t know at what point in that relationship, you would make that suggestion, if you’re a provider, you know.” (p 44)*

### **Family Views of Consumer Recovery**

Overall, family members differed from one another in their views of recovery for their adult children. Therefore, the theme that emerged here could be summed up by stating that *recovery is more than what meets the eye* according to parents in this study. First, views of medications and recovery will be presented in this section, followed by general views of recovery within narrative and survey data.

### **Recovery is More than what Meets the Eye**

#### **Medication and recovery.**

Each parent offered a distinct perspective about medications and recovery. Across cases, each family member agreed that medications were a part of their adult children’s ability to live their lives. However, some also alluded to the incompleteness of medications relative to helping their children function. When Sheila was asked her thoughts about recovery from mental illness, her first response integrated thoughts about the chronic nature of the illness and the necessity for medication:

*Sheila: “Well, unfortunately I haven’t read anything good [about recovery]. I understand that these illnesses are chronic, they are debilitating, that they require medication, that they haven’t reached the point where they can say okay, you haven’t had*

*symptoms for while so you probably don't need your meds. It's often quite the opposite. You haven't had symptoms so thank God and keep taking your meds." (p 33)*

Sheila offered her perspective of whether and how medications link to Dan's ability to persevere in his life:

*Sheila: "Yes, [medications] have [helped] as only from his perspective. See I can't really say because if you ask me, I don't know what he's going through from minute to minute and what difference the medication has made to him. From where I sit, yet, he functions and he functions at a very high level I think. And I think that this is because of the medicine and when he's not on it, he cannot function and that's the difference." (p 36)*

Although Dan may have held initial hopes for his medication to be a cure, Sheila thinks that his ideas may have evolved in the course of his many experiences:

*Sheila: "And I'm beginning to think and I think he feels that that may be the case that there isn't a combination of drugs out there that will make it any easier, it's just that you have to deal with it." (p 36)*

Sheila believes that a cure for schizophrenia is not hopeful at this time. The best hope is the invention of a medication that resolves symptoms more completely:

*Sheila: "Well, even in the literature where they're trying to be so positive. The underlying feeling I get from it is that there isn't a good outcome or a change in outcomes; that it's something that's going to be a problem forever unless they finally do find some medication that's better. I haven't seen anything positive." (p 34)*

*"Right, the recovery literature says, oh there's hope out there. There's medication for you. You'll feel better and I think to be honest, that's about all they can say. They don't say oh, you'll feel better for awhile and then you'll crash. And so I think every good day is really important and maybe the more good days, I don't know." (p 34)*

Maureen feels that the medications have helped her restore more normalcy to her life, as presented in previous sections. However, she noted an interesting dynamic with medications in her observation that Rebecca does not seem to be upset about not working:

*Maureen: "She just, I'm sure it's affecting her sense of self. You know. She seems, she really, I'm amazed at how chipper she can be at times and how accommodating and all*

*that, because if I was where she was right now, I'd be sick as a dog, I think. But maybe that's the medication working and that's what I try to tell myself..." (p 39)*

Maureen worries when she sees that her daughter's routine is unpredictable and that regular work is not part of her life:

Maureen: *"She wants to; I mean she needs a reason to get up every morning. She's spending more time sleeping late; going to bed early...it seems to be we're slipping a little bit in terms of the recovery now that I think about it. I mean, I've given it a little thought in the past couple of weeks, but you know she, her sleeping patterns aren't the greatest right now. Some days she'll get, in the morning she'll get up and say she didn't sleep well last night and she'll spend a little extra time in bed and I try not to, you know, I don't, I try not to get her upset about that, but whatever she feels like doing, she does..." (p 39)*

Richard commented on how medications play a role in recovery, as he reflected on how medications were the right decision for him:

Richard: *"I think they fit very well because it's just a question of finding the right one and then hoping and praying that it remains the proper dose you know. Even if it doesn't, you have to tell yourself that you're going to keep taking it until you get something different and then try to go with something new, you know." (p 32)*

Paul offers a different perspective of medication as he considers the potential of other wellness strategies:

Paul: *"Well I think all of those things could work well in conjunction with each other. It's not, this is better than that, that's better than this. You can have all of that, everything that helps that individual stay well is useful." (p 40)*

### **General views of recovery.**

Each family member had a number of ideas concerning aspects of recovery that are perhaps more indirectly linked to medications, per se.

*Narrative results.* Maureen and Sheila were most similar to one another in their recovery beliefs as they discussed the harsh reality of their children's difficult lives with mental illness. As will be presented, their views integrated a mix of cynicism and hope. For her son, who has struggled with many relapses including his most recent 2 ½ years ago, Sheila wonders if the recovery model acknowledges the intense hardship for Dan:

Sheila: *"For him to have had what I would say is probably four major breaks is many, many more than statistically he should have. And I understand people having one and then, but to have two the prognosis is a little worse and if you have three, it's even worse and he's been through this many times...so it's so fatiguing to deal with this illness that it scares me to death because sometimes I know he's so tired of it."* (p 34)

Sheila had much to share in regards to her perceptions of Dan's mental illness, including his last relapse that seemed to affect his cognitive abilities:

Sheila: *"When I see Dan struggle over the last three years since he had this second acute problem. His IQ has changed. His ability to deal with practical issues has changed. Up until that time, he still was of a very high intellect and able to do work and set up a database and do all kinds of things with responsibility, to keep track of what was going on in his life and thought processes. Where now the last three years, it's like it just wiped that out, and he's gaining it back but it was a terrible, terrible setback for him."* (p 4)

She reflects on both of her sons' illnesses, comparing the challenges of physical versus mental disabilities:

Sheila: *"With Dan, it was like it was such a profound change that it wasn't like how did this affect his life, it was more like this is his life and how do you deal with that? [His brother's] disabilities are equally as profound, but it seems to me that it is more difficult to deal with mental illness than it is physical disabilities...I'm sure they look at each other and wonder how they do it, because it is very challenging."* (p 3)

In the midst of such a difficult course of illness, Sheila expresses her visions of hope:

Sheila: *"We only talk to each other hopefully. I mean, I think he's tired and I think sometimes are better than others, but we only talk about well you know, 'you haven't*

*been on this [medication] long enough to know if it's going to be more helpful or maybe you should talk to somebody about this..." (p 34)*

And pride:

*Sheila: "I mean, bless his heart from having to drop out of high school, getting his GED, going to community college, going to university. I mean he's just been, well, he's a wonderful person." (p 35)*

*"Um, I think that I'm always conscious of Dan's value as a person and what a fine character he has and how thoughtful he is and I think that I'm very proud of him and the work that he's done and what he's had to overcome. But I wish he didn't [have to], of course." (p 37)*

*"It's a horrendous thing, it's just horrendous, but I just give him so much credit. He just, I wish other people knew him the way that I do because he just deserves so much credit and I mean hero's too often used, but he is just heroic to me. His daily struggle and the work he goes to..." (p 37)*

She commends him on his engagement in life occupations:

*Sheila: "Well, Dan has said that over time he's learned to live with the symptoms. That if things are going on in his brain he can get past that, that he can...and I think that's his mechanism for winning over his diagnosis is that he can learn to live with it by adjusting his consciousness or his experience. But he really does things like the poetry reading, and his writing, and things like that that do make his life worthwhile; and his volunteer work he loves. I think he really enjoys doing the work with NAMI." (p 35)*

Maureen reflected on her views of recovery, also noting the notion of chronicity:

*Maureen: "I'm gathering from what you've told me and what others have told me is that nothing is permanent about recovery, okay? You know, I don't like the thought of that. I like the idea that you should be able to take this medication, get rid of the symptoms and move on with your life on a step-by-step basis. I realize I need to learn more about recovery. In many ways, Rebecca seems to have recovered. But I realize she is very susceptible to relapse especially if stressed too much..." (p 37)*

She wonders if some of Rebecca's recent ideas about cure of schizophrenia have

stemmed from any of her recent treatment sessions:

*Maureen: "She keeps coming back to the fact that somebody has said that she will not, a therapist or someone, has said that she may not have schizophrenia all her life, that it can go away. And this goes back to my distrust of some of the; I don't know whether that's true or not, but if some therapist has told her that, and that's not true, that's a heck*

*of a disservice, you know. Because you know she has to put it all together and not have any pipe dreams here, okay. Yes, there's treatment. Yes, you can go on with your life if you stay in treatment and understand what the pitfalls are and get back into it if you need to, but don't be under the illusion that you're ever going to be cured... You have to know what you're dealing with in order to deal with it and if you're going to be not clear about what it is, then you know, you can't work with it." (p 42-43)*

Since she has not been invited to her daughter's sessions, she is left to imagine her provider's role in her recovery:

*Maureen: "I'm just wondering what people are doing to help her in her recovery right now because they're not bringing me in on it, and I'm the one who interacts with her more than probably anybody else right now. So I mean, I guess you can catch my cynicism in this okay? [LAUGH]" (p 38)*

Richard, who lives with schizophrenia himself, promotes faith and support as key features in recovery:

*Richard: "Well I just think that you have to put God first, and I put God before my children, and all my work or my anything, you know, you just have....like my mother used to say, you know, I can see you going down, down, down, and I'll be going up, up, up in the afterlife and I won't be able to pull you up, you know...Yeah, and I just pray for them all the time, and it really works. It really does." (p 29)*

*"Yeah, [mental illness] is really a mysterious thing now, very mysterious. I don't think they'll ever really explain it, you know. But I always say, they say we're going to change people one heart and mind at a time. I think they have to start with the soul...I think the illness is more of a side, you know. It's not really who you are, no." (p 34)*

He also believes in Alison's ability to move forward due to her current support system:

*Richard: "I think it's possible. I mean, she's got a wonderful husband. I don't know if you met him...He's wonderful. He's got a wonderful way about him. His mother is a wonderful person, she's had a lot of influence on him..." (p 30)*

Interestingly, he thinks that Alison's dog has been a part of her recovery:

*Richard: "Yeah, poor child. She got SSI for a couple of years and we got her the dog. The dog helped a lot." (p 30)*

Richard also feels strongly about necessity to resolve stigma around mental illness:

*Richard: "No, I would just like to say, I think you have to really get to know the individual aside from his or her experience and the thing I find most difficult is trying to live down your experiences. The impressions you've made on people sometimes, you*

*know, which are not the best impressions, and sometimes they get the wrong impression about a person with mental illness and they say, they must be a child molester; that's the first thing they think, you know, must be some kind of a monster or serial killer or mass murderer. That's a lot of bull, you know? But it's hard, it's very hard."* (p 34)

Paul, who often draws parallels with his own treatment for alcoholism, centers on the hard work involved in the maintenance of recovery:

*Paul: "Oh, from my point of view, recovery is an elimination of all dangerous behavior. Reach your level of self-sufficiency. It's not what I think you should be doing, it's what you're able to do for yourself. And do all the things that help you maintain that level of recovery. You know, you just don't, being a recovered alcoholic, one of the first things that you do when you recover, is you go around your old [INAUDIBLE] just so you can show you can show your people, look how well I'm doing. Aren't I doing great? See what happened when I stopped drinking. Isn't that terrific? You know and you keep going back over that, oh we got some beer, and I think I can have one, one beer, don't have a problem, wrong. You got to maintain the things that got you there, in my thinking. So the things that got him to the point of recovery, he has to maintain that. You ain't well, just like I ain't well, it don't take but a teaspoon of vodka and I'm off to the races, you know. So, you just got to do the things that work. Let's just say, you need to dance with the girl that brought you to the dance or something like that, the person that brought you to the party, that's the one you should dance with, something like that, that's the one you should do with; same thing with recovery... The same stuff that made you well or got you to this point, continue to do that. You know, so that's my point. Consistency in following a schedule, a schedule recovery program. You know, I think or it can't just be like maybe you do this, or maybe you do, he's got to be consistent and I think that's helped a lot... Oh I think it's important that he stay in touch with family and friends. And maintain a regiment of medication, if it's the right medication."* (p 34-35)

Paul believes recovery does not equal complete cure from symptoms:

*Paul: "That's pretty accurate, you know, especially the part that you said about or at least still may have symptoms, nobody's perfect. We've got folks that's walking around that's never been diagnosed, that should have been diagnosed, so you know, and they function. So you know, and that's the same thing with folks that have been diagnosed."* (p 40)

He also feels that removal of stigma is an integral part of recovery:

*Paul: "Yeah, well there's one of the steps in the program is once you have obtained your level of sobriety, it's pretty much your job to pass that along to somebody else that's still not just suffering, and I feel like a lot of the stigma around mental illness could be eradicated. If people with mental health issues start talking to people that have it as well, as they look, it's pretty good on this side, and our therapist's office, there's a big poster up on the wall of celebrities that had the courage, you've probably seen it, to come out and let people know, that look I'm confronted with this, that doesn't make me bad."*

*Mental illness is not a crime; you're not a criminal because you're sick. If you got a heart problem, that don't make you a criminal. So you got schizophrenia, that don't make you a criminal, you know."* (p 37)

**Quantitative results.** Each parent completed the Recovery Attitudes Questionnaire (RAQ-21) [Steffen & Wishnick, 1999] for the purpose of assessing their general attitudes of recovery. Total raw scores were computed, along with percentages as seen in Table 5. Figure 10 illustrates the reduction of factors to two, including "recovery is possible and needs faith" and "recovery is difficult and differs among people."

Relative to general attitudes about mental health recovery, families 1, 2, and 3 (Sheila, Maureen, Paul) scored within 3% of one another (76%, 75%, 73% respectively). Family 4 (Richard), a consumer with schizophrenia as well as the father of Alison, scored distinctively higher (88%) than other family participants.

Table 5

RAQ-21 Total Scores: Families

Participant	RAQ-21 Total Score (out of 84)	RAQ-21 %
Family 1	64	76%
Family 2	63	75%
Family 3	61	73%
Family 4	74	88%

RAQ-21 (Steffen & Wishnick, 1999)

Reduction of the RAQ-21 to two underlying components (*Figure 10*) yielded similar results between family 1 and 2 (Sheila, Maureen), which was also the case with consumers 1 and 2, as illustrated previously. Family 3 (Paul) scored lowest of all the families for both factors, including "recovery is possible and requires faith" and

“recovery is difficult and differs among people.” Again, Family 4 (Richard) scored higher than all of the other families within both factors. Like consumers, families in this study scored higher in their view that “recovery is possible and requires faith” versus “recovery is difficult and differs among people.”

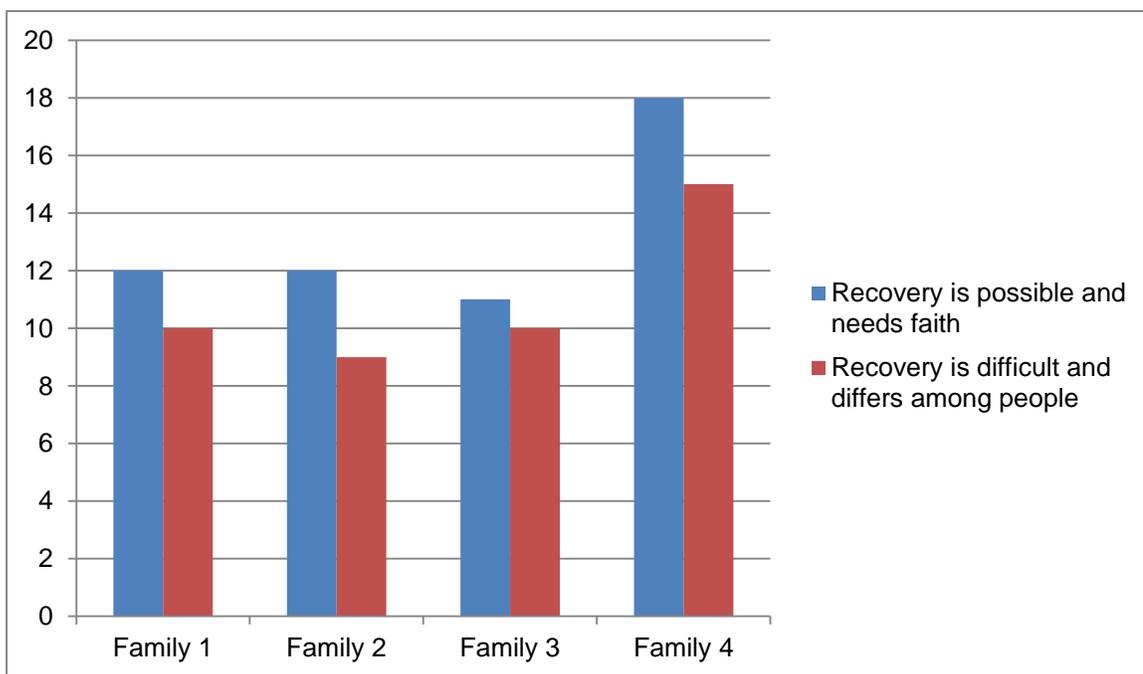


Figure 10: Recovery Attitudes Questionnaire (RAQ-21) Factor Component Scores for Families. This graph illustrates scores indicative of general beliefs of recovery, reduced to two factors, for families across cases (Steffen & Wishnick, 1999).

A bar graph is shown below (*Figure 11*) to compare consumer and family attitudes of mental health recovery using two reduced RAQ-21 factors. Dyad1 (Dan, Sheila) scored equivalently while dyad 2 (Rebecca, Maureen) was roughly equivalent with one another in their attitudes about recovery. Discrepant viewpoints were seen in dyads 3 (Sean, Paul) and 4 (Alison, Richard). Specifically in dyad 3, the consumer indicated that he supported ideas of recovery within both factor domains to a greater

extent than did his father. The opposite was true of dyad 4, as the consumer indicated less support for ideas of recovery within both domains than did her father.

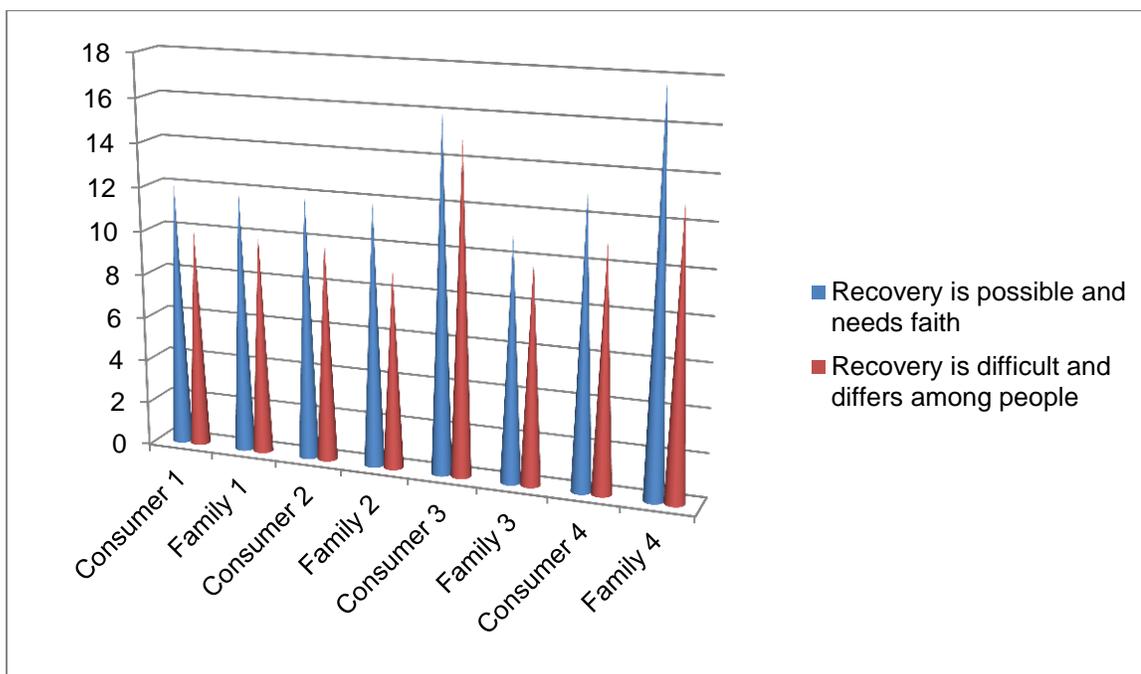


Figure 11: Recovery Attitudes Questionnaire (RAQ-21) Factor Component Scores for Consumers and Families. This graph illustrates the comparative scores of consumer-family dyads of the RAQ-21 factor components (Steffen & Wishnick, 1999).

### Conclusions

In review of the consumer participant results, it appears that there are two global themes that encompassed the many themes brought forth. The first global theme (*Figure 12*), which encompassed portions of their text that were explanatory of medication adherence, is the *merger of medications as an imperfect instrument of self-care*. This theme included aspects of how consumers developed self-awareness through oppressive discovery, and how they experienced the permeation of fear and insecurity around medications. Each consumer utilized imperfect medications as one way to take care of themselves, but taking medications was wrought with powerful emotion.

The second global theme for consumers in this study (*Figure 12*), which contained portions of text indicative of ideas regarding social support and recovery, is their experience of being *wedged between illness and freedom*. This theme included content that focused on their desire for autonomy, boundaries of family involvement with health, and influential but disappointing experiences with providers. Consumers shared how they were metaphorically stuck as they attempted to live with mental illness.

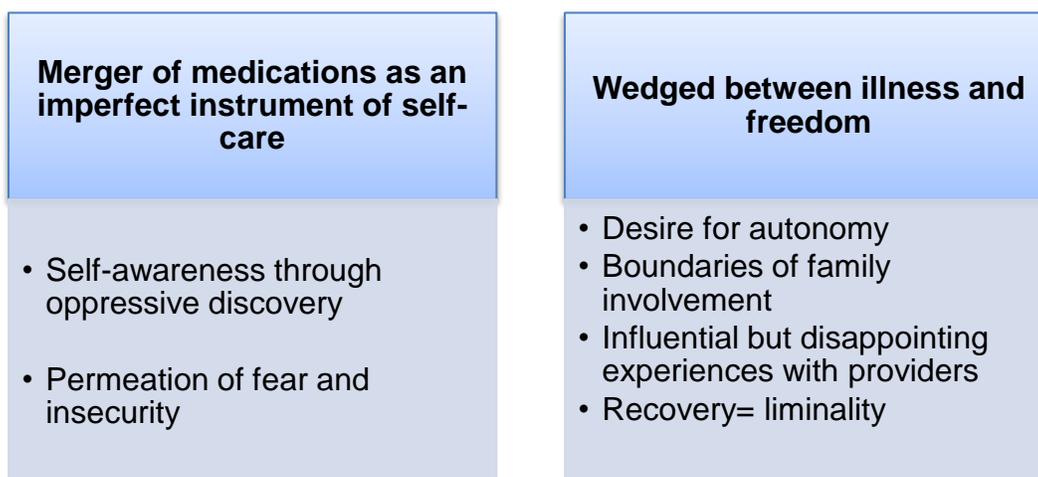


Figure 12: Emergent Global Themes for Consumers. This figure illustrates the overarching themes that surfaced through exhaustive analysis of consumer data.

Family participants in this study offered equally passionate perspectives about medication adherence, social support roles, and recovery for their mentally ill adult children. Their supporting text revealed challenges of parenting their adult children while waltzing to the *puzzling dance of separation and support*. They also shared opinions of the *absolute necessity of psychiatric medications* for their children and the trials of communicating with providers in the *abyss of family-provider discourse*. Parents in this study also summed up their vision of recovery for their adult children as they

explained that *recovery is more than what meets the eye*. Across cases, recovery was expressed most incongruently when compared with the preceding themes.

The following chapter will aim to discuss consumers' and families' experiences with medication adherence, social support, and recovery in reflection of the data in connection with literature and theories. Implications for the field of occupational therapy will be discussed. In addition, research limitations and future recommendations for research are presented prior to concluding the study.

## CHAPTER 5: DISCUSSION

The goal of this dissertation study was to understand the complex phenomena of medication adherence, social support, and recovery from the perspectives of consumers and their families. In this chapter, the main findings of the study will be discussed and compared with existing literature through the lenses of PEO (Law et al., 1996) and recovery models (Anthony, 1993). Next, the chapter will move toward discussion of methodological considerations, implications for occupational therapy and occupational science, and future research recommendations.

### **Consumer Experiences with Medication Adherence**

This study set out to first examine consumers' experiences with medication adherence. According to results in this study, consumers' experiences with their psychiatric medications were captured within the global theme of *merging medications as an imperfect instrument of self-care*. Merging medications into their lives seemed an appropriate metaphor to describe a gradual but intense shift toward taking medications with truly little option to refuse. As in a merge point, one must go forward even if they choose to "get off" at the next exit on the road.

This is in contrast to language that may have implied internalization or true integration of medications. Some consumers merged medications rather swiftly into their lives, and some incorporated them progressively. It was apparent that consumers in this study decided to take medications to help manage their illness, but that such a decision was not based on restoration of pre-illness states or lack of ongoing challenges. In fact, medications were seen as imperfect but simultaneously useful tools to take care of themselves.

Sub-themes included consumers' development of *self-awareness through oppressive discovery* and the *permeation of fear and insecurity* relative to medication and other aspects of their illnesses. Self-awareness through oppressive discovery was essentially consumers' processes of learning to manage their illness, one of which is medication adherence. They developed self-awareness as an experiential process, one that happened as they lived life with their illness.

However, the way that consumers developed this self-awareness was not a pleasant journey. The discovery was oppressive, which implies the presence of a heavy emotional burden for consumers. Permeation of fear and insecurity denoted consumers' sense of uncertainty about their medications. For example, consumers wondered if medications would continue to work or if effects would fade over time. Conversely, some worried about adjusting medication doses, even downward, for fear of tipping the equilibrium against their favor.

The occupation of medication adherence for consumers included both person and environmental components (*Figure 13*). The consumer's beliefs about health and medication (P) interact with generational family beliefs about mental illness (E). According to PEO, a person is composed of mind, body, and spirit and is influenced by his life experiences (Law et al., 1996). The "person" is inclusive of one's personality, competencies, self-concept and culture. Competencies include one's abilities while also considering the particular health condition (Law et al.). The environment includes cultural, socioeconomic, institutional, physical, and social components (Law et al.; Rigby & Letts, 2003).

The identification of these components in the occupation of medication adherence is consistent with the concept of a transactional relationship among person, environment, and occupation as stated in the PEO model (Law et al., 1996). To discuss consumers' experiences in-depth, this section will next highlight both person and environment components as deemed significant within sub-themes.

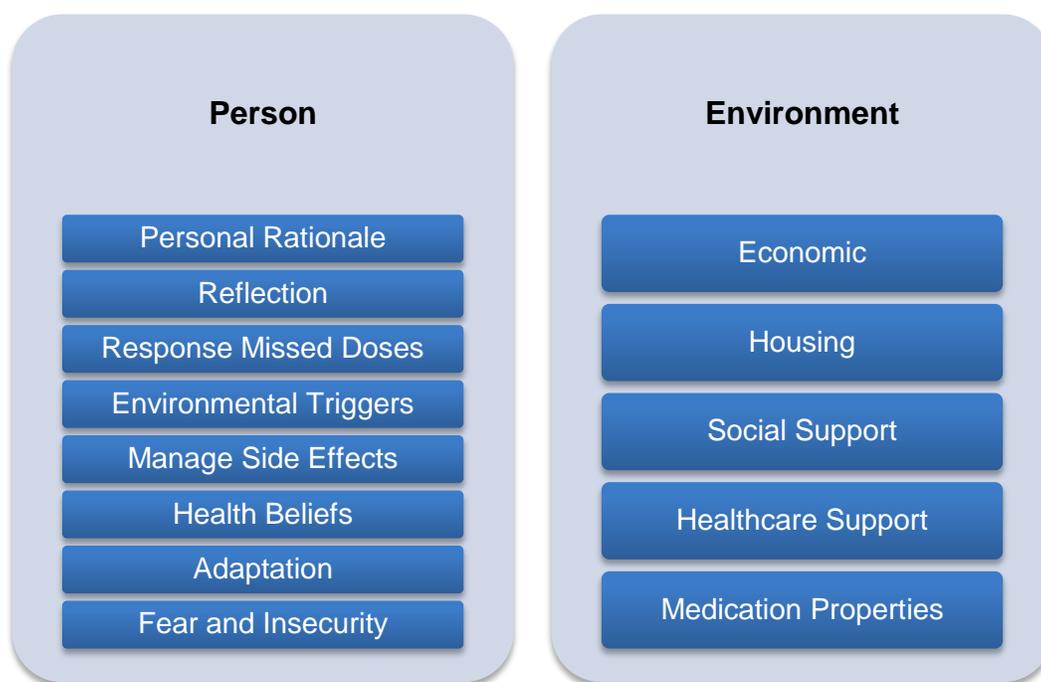


Figure 13: Personal and Environmental Considerations in Medication Adherence. This figure illustrates the vast array of features as experienced within the contexts of self and environment.

### **Self-Awareness through Oppressive Discovery**

Characteristics and beliefs of each consumer in the study played key roles in their own processes of acquiring awareness of the effects of their illness, how they would manage it and make health decisions accordingly. The physical and social environments were also indicated by consumers as influential to their development of self-awareness, though they were not all positive. The “merger” of facing the decision about medication

adherence happened differently for each participant, which is consistent with literature on recovery. Despite the unique chronological timeline of adherence, it seemed that consumers incorporated medications as a distinct process rather than a point in time. This finding is reminiscent of the recovery process itself.

For consumers that did not readily adhere to medication at the beginning of their illness timeline, a process of self-awareness developed as they experienced difficulties of life without medication. Consumers who adhered at the outset of their illness course also experienced a process of self-awareness as they managed their illness alongside medication side effects and/or psychotic relapse despite medication use. Notably, consumers who adhered did not refrain from contemplating non-adherence or feeling desperation related to challenges with medication use.

### **Decision-making.**

Two consumers with schizoaffective disorder, Alison and Dan, experienced medication adherence rather consistently since the onset of their illness. Dan was especially committed to using medications and Alison endured one brief episode of non-adherence to her anti-depressant early in her illness. They each offered their personal rationale underlying their choices to take medications. Each consumer was unique in the way they experienced this process.

Dan made a swift but difficult decision to take medication during his first hospitalization. He participated in his own cost and benefit analysis, weighing his worry about long-term side effects of treatment with the effects of living with severe mental illness. Despite his father's opposing view of medications, Dan decided that his father

must not be thinking clearly. Dan wondered, did his father not remember the impact of his family's history of schizophrenia? He decided that he did not want to be hospitalized indefinitely or commit suicide as a result of illness. As a young adult, his beliefs about medication and health framed his emergent process of coming to understand what is needed to manage it. The way Dan approached this decision is consistent with the idea in recovery that consumers have the right to become informed and be active agents of their healthcare (Anthony, 1993; Deegan, 2005).

He also considered that he was not alone in his struggle and that other people surely had this illness and took medication for it. Dan also did not relish the thought of becoming psychotic again, fearing relapse. He continues to take medication because it is efficacious in managing his paranoia and auditory hallucinations. His last relapse incurred greater cognitive impairment and more difficulty accomplishing his goals in life. Living with side effects of his medication has been a challenge.

Alison was the more ambivalent of the two, expressing polar viewpoints about medications throughout her interview. She started taking medication at the onset of her initially diagnosed depression, but was not hospitalized (nor was she ever). "Something told her" to stop taking her anti-depressant and a "big nervous breakdown" resulted. She began medication again, stating that "it sucks" but continues to take it because it helps her to work and to fit in socially with her co-workers.

On the other hand, she feels that society forces her to take medication that makes her a different person. If anyone is the slightest bit different, she explained, society wants to put you in a box. She is also disgusted with her excessive weight gain. Alison still

feels grateful for the availability of medication to ease some of her illness symptoms. Alison reflected on her exposure to the traumatic event of losing her mother to suicide as a result of untreated Bipolar Disorder, and her father's many years of non-adherence that resulted in her support of his involuntary hospitalizations. This generational history cannot be undone, and seemed to be a part of her decision-making equation.

Sean and Rebecca, diagnosed with schizophrenia, experienced a rockier course in their decisions to adhere to medication. Sean used medications sporadically for the first part of his illness, including antipsychotic injections. For the most part, he spent more time off medications than on them. After his illness got the better of him in the presence of his father and his stepmother to be, Sean became homeless for what would be many years. For these years, he was medication-free, living on the streets and in shelters.

Sean eventually grew tired of his repetitive cycles of incarceration, hospitalization, and return to the streets. This was his reason for finally trying to stay on medication. He is still very unhappy with the weight gain, as he also was when he was offered them during his many previous hospitalizations. He stays on the medication, but does not know how much of his improvement can be owed to medication versus having stable housing.

Rebecca's decision to take antipsychotic medication to manage her illness was a process that including finding an accurate diagnosis. She trialed medications for what she thought she was struggling with, Attention Deficit Disorder. When she finally learned she had schizophrenia, she was willing to try taking a medication known as Risperdal. This caused bothersome side effects for her and she felt she was getting worse

instead of better. She serendipitously stopped medications as she planned avenues to find new medication.

Her mother found Rebecca doctors that were acquaintances of the family, which Rebecca did not take kindly to. Her illness worsened, resulting in an acute hospitalization which led to a voluntary research hospitalization. Rebecca decided to try a new medication because “she knew she needed it” and respected the doctor who was prescribing it at the research hospital. She continues to take the medication because she feels balanced and as though she can “do normal things again.”

Each of the consumers in this study made a conscious decision to take medications, but under different circumstances, timelines and using a variety of approaches. They each actively participated in the decision to take medications. This finding is comparable to Marland and Cash’s (2005) study that addressed adherence patterns for individuals with schizophrenia versus physical conditions such as asthma. Their study found that both groups of participants rivaled one another in their decision-making strategies while utilizing a variety of styles. They found that decision-making is a process, whether the person lived with schizophrenia or a physical disability while also pointing to the need to be informed about distinctive features of different health conditions.

The findings of this dissertation study are also in line with a study by Roe et al. (2009) which sought to understand rationales for medication non-adherence from consumers who stopped medications and remained off medications. Consumers’ decisions to stop medication were due to negative experiences with medications, or

opposing viewpoints with their physicians. Their decisions by consumers in their study were based on a cost benefit analysis prior to deciding to stop medications. Like Marland and Cash's (2005) study, they also found that decision-making was a multi-step process.

Although inclusion criteria differ with Roe et al.'s (2009) research, consumers in the current study also exhibited coherent views of both stopping and starting medications. Although consumers sometimes revealed thoughts that implied symptoms could have been present (i.e. "something told me to stop taking it"), their rationales by and large indicated logical thinking (i.e. gaining excessive weight; not getting better with medication).

Even in difficult situations such as facing an opposing view of a parent about medication, such as occurred in Dan's case, sound decision-making processes were demonstrated. In the case of Rebecca, an intermingling of logic and symptom-based thinking may have been in play for portions of her adherence story. For example, the side effect of losing her menstrual cycle may have been particularly bothersome to her partially based on delusional thinking or paranoia. However, she also clearly stated that she would one day like to have a "normal life" which included getting married and having children. This is a reasonable hope for a young woman, whether or not others believe that will happen for her.

The finding in this study about self-awareness also brings to light the issue of insight that is so popularly covered in the existing adherence literature (Holzinger et al., 2002; McCann, Clark, & Lu, 2008). Insight was not measured as part of this study, but the finding of self-awareness and the ability of consumers to participate in complex

decisions about their healthcare (Marland & Cash, 2005; Roe et al., 2009) leads one to wonder whether insight is needed to accept medications? If insight is a predominant influence, which aspects of insight are most helpful in medication decisions? As Davidson et al. (2009) stated, most individuals with severe mental illness and poor insight are still keenly aware of the fact that their lives have been turned upside down. Dan himself made a strikingly similar comment in his interview, in fact.

Sean, who probably least reflected on the severity of his illness and need for medication, was offered medication many times during his revolving door hospital admissions. Insight into how ill he was, as evidenced by his resultant homelessness and unprovoked fights with strangers, did not seem to play a role in his perceived rationale to take medication. He did not reveal that anything was different about this hospitalization as compared with his numerous others. All that seemed to be required for his change of adherence was his fatigue over repetitive cycles. Of course, this rationale could certainly contain an underlying meaning about his desire to have a better life. But the data reveals a much simpler notion, which is all that can be said.

During her interviews, Rebecca also did not demonstrate insight into the links between her illness and difficulty functioning in life. However, it seemed enough for her that she experienced a return to “balance” when she finally found a good medication fit. As mentioned, Rebecca also respected her doctor who was at long last not associated with her family. Rebecca went so far as to say that it is “exciting” to take medication when it works. Like Sean, this expression does not seem to indicate that astute insight into the illness of schizophrenia was part of her equation. What she did realize, however,

is that the medication helped her. She must have had enough awareness to know that her life was different than she wanted it to be.

This study did not support a previous finding that families play a predominant role in negative attitudes toward medications (Santone et al., 2008). As a child, Alison endured her mother's suicide from non-adherence to Lithium. She became her father's guardian during his involuntary admissions for severe psychosis from non-adherence to anti-psychotic medication. Alison still decided to take medications for herself, and is pleased that her father came to a decision to adhere. Dan's father expressed disparate views about medications and mental illness. With Dan's desire to please his father, one may think that he would also hold a negative opinion about medications and side with his father in refusal of them. However, he resolved to take medications despite difficulties he faced within his social support system.

### **Illness Management.**

The ongoing daily decisions about medication adherence assisted the consumers to build understanding and skill to manage their severe mental illness. It was apparent in this study that consumers gained awareness as they lived with illness, both while they adhered and non-adhered to medication. They learned about their illness not via lectures, but through daily life with schizophrenia or schizoaffective disorder.

Noticeably, consumers developed self-awareness through trial and error (or trial and success). For some consumers, more trial and error with dire consequences resulted. They learned the hard way (Sean, Rebecca). For others, they took falls and stumbled without as many severe consequences (Alison, Dan). This insight is reminiscent of

typical adolescence and emergent young adulthood where the stakes are higher because the person is now fully responsible to bear the consequences of the decision in the search for his or her identity (Carter & McGoldrick, 2005). Some will inevitably choose the long, hard road.

The development of self-awareness regarding the occupational of medication adherence involved overlap of person and environment components as upheld in the PEO model. If one were to view the fit between person, environment, and occupation for each consumer, it would be apparent that each one would look at least slightly different. The PEO model sheds light on consumers' similarities relative to the three components, while the recovery framework supports the individual expression of these likenesses.

In the course of learning about their illnesses, it seemed some consumers attributed more influence to environmental influences, and some to personal. They each experienced the development of self-awareness in a dynamic, non-linear fashion, likely with more exaggerations than typical due to the relapsing nature of schizophrenia. This dynamic experience also parallels concepts supported by the PEO model (Law et al., 1996).

Dan is a good example of a consumer who attributed a combination of person and environment characteristics to his process of learning how to take care of himself. Person features were very intense for him, as the illness experience overtook many of his senses. Although he acknowledges that his medication has helped him a great deal, he has also endured periods of time when he perceived his medications to be increasing his psychosis. When he had the occasional experience of forgetting to take his medications,

he learned to anticipate his consequences, including feeling as if he was on an “emotional roller coaster.”

Dan also learned that adaptation of leisure activities, such as playing guitar, was necessary as it caused him to feel internally disorganized. In terms of environmental influences, he discovered that certain triggers contributed to his relapse in addition to medication changes. This included his living situation with his mom and stepfather and his stressful work situation.

Sean also endorsed person and environmental influences involved in learning how to manage his health condition. However, Sean’s PEO fit would seem to include a larger “E.” He emphasizes the vitality of housing and social support in order to manage mental illness. He was certainly impacted by his experience of homelessness, which is known in the literature to be a predictor and outcome of medication non-adherence (McCann, Clark, & Lu, 2008). He does not give as much credit to medications for his ability to improve. He spends time talking about personal influences, mainly the impact of weight gain on his sense of self. He explains how he does not like the image he sees in the mirror. This negative experience has contributed to his development of the belief that one should not have to choose mental health over physical health. He even goes so far as to say that homelessness, though not ideal, was at least a supporting factor in his ability to keep himself physically fit. After all, he could walk the length of Manhattan two or three times a day.

Rebecca also recognized both person and environment influences in the experience of managing her illness. Person factors were mostly described as the

experience of side effects from medications, such as the strange disturbance of her menstrual cycle and nightmares. As described previously, Rebecca may have been particularly annoyed with the disturbance in menstrual cycle as it related to her sense of meaningfulness in her life, relative to her desire to have a family. It is possible that her paranoia could have been elevated in the sense that she could feel like she was being sterilized. Nevertheless, this side effect became a significant part of her personal experience with medications. Environmental influences were also significant, namely the perceived over-involvement by her mother to find doctors who knew the family and her mother's insistence that she "just take the medicine" even though Rebecca perceived that it did not work.

Alison's experience of learning to manage her illness was also shaped by both person and environment influences. Her personal experience was also very intense, especially as it related to her sense of self related to weight gain. This suffering has contributed to her belief, similar to Sean's, that one has to choose being "fat and docile or crazy and skinny." She goes a step further in saying that she feels that she is a "sheep" implying that she needs to follow blindly, accepting whatever fate comes her way. This "catch 22" concept is supported in the literature (Jenkins & Carpenter-Song, 2005).

Although she expresses ambivalent thoughts about fitting in at work, Alison continues to feel she is talked about by her co-workers, mainly about her weight. She does not ascribe this experience as paranoia, but one that is reality-based. In terms of environmental impacts, Alison wonders if her illness would even be part of her if she had better economic circumstances. Furthermore, she explained that better financial ability would possibly remove her need for medication altogether. She has also recognized

triggers in the environment that lead to symptoms, such as exposure to the children at work for too long. Therefore, she has learned to take breaks when she needs them.

Each of these consumers merged medications into their lives to help with managing illness. However, as their data alludes to, medication was not a quick fix. No magical improvements were experienced by the taking of medication. In fact, each consumer is left to manage remaining symptoms, such as lack of energy (Alison) and social withdrawal (Sean, Dan, Rebecca) as they explained in their interviews. This finding is in line with studies that have found medication to be more effective with positive symptoms than negative symptoms (Johnson, 1998; Shean, 2004). And, as three out of four consumers attested to, managing excessive weight gain as a result of antipsychotic medication was indeed a troublesome side effect. The “effects of the side effect” were integral to their sense of self, the person they saw in the mirror each day.

As imperfect as medications have been for each of these consumers, they have decided to incorporate them as an aid to manage at least a portion of their illness symptoms. It is not the case that they have chosen a miracle cure for themselves by taking medication, but it appears that it is an option that will do for now. Medications are not something they would have chosen for themselves had they not been unexpectedly handed their chronic illness.

Sometimes, in the course of learning about their illness, beliefs about health and medications have illustrated development and change. For example, Alison thought that taking medications for the first time was “like the end of her life.” Now, she feels “it is her job” to take care of herself by adhering to her medications. Although she thinks

about stopping medications, she states that she would not do so without a doctor's help. Dan began his journey feeling devastated, but also hopeful that he could be okay for the rest of his life as long as he had support and medications. Now, he believes that, although "medications have been destructive," he accepts it as "something he has to do." Dan explains that he now has a "better idea of what kind of person he is." These are lessons in their lives that have come with time and experience.

All consumers have stated in one way or another that they intend to stay on medication for now. Of course, merging medications into life does not imply guaranteed permanence. One can always find an exit on the PEO expressway. However, the use of symbolic gestures by some of the consumers was a surprising finding in this study. Sean symbolized his commitment by showing his father the pill in his mouth, and by carrying an old jail identification card as a reminder of where he has been and where he is now.

Dan was able to give simulated advice to other consumers who may be wrestling with the idea of taking medications. Considering what is known about schizophrenia, including drop in IQ, poverty of thought and speech, and tendency for concreteness (Hirsch & Weinberger, 2003; Torrey, 2006) the use of symbolism appears to be a somewhat abstract way of inspiring the self or others. This specific topic did not arise in the initial literature review beyond the expression of medications or family members as symbols of one's disability (Lefley, 1997).

### **Permeation of Fear and Insecurity**

Through their vivid descriptions of life with illness and medications, consumers explained how their daily lives could be so uncertain, full of strong emotions such as fear.

As shown in consumer data that emerged in this study, their emotions fueled their hopes and expectations concerning medications. According to the PEO model (Law et al., 1996), these emotions were heavily personal, with a few indications of environmental influences. In the literature, fear was not a concept that emerged regularly around medications.

One particular study by Marland and Cash (2005) found that consumers, in the process of decision-making, reacted through a mechanism of fear of relapse. The findings in this study, especially relative to Dan's fear as a primary driving force in adherence, are cogent with Marland and Cash's study. However, the consumers in this dissertation study revealed that it is not only a driving force for fear of relapse, but fear is present in other idiosyncratic ways.

Interestingly, this fear could be communicated in language implying hope. For example, Dan was willing to live through the intense initial first weeks of taking Clozaril, believing that this medication may be his last chance. He hoped that by tolerating the worst beginning side effects, he would come out better on the other side. This concept is reminiscent of Karp's (2006) research that implied analogous ties between medications and love relationships. Although Karp's participants did not mention fear per se, they did express the initial hope of finding a medication that worked, a love relationship that began with the honeymoon phase and could eventually end in "divorce" (p. 64). Even when the initial effects seemed to lessen and Clozaril seemed to prove its efficacy in managing symptoms, Dan worried whether the medication would "wear off" as he had previously experienced with Zyprexa.

This type of fear was similar to Alison and Rebecca's reluctance to adjust their medication doses. They feared that making a change in their dosages would induce negative effects or negate the positive effects. Rebecca explained that her physician proposed lowering her Abilify dosage since she was doing so well. However, she is aware that she can have "lapses" and does not want to upset the apple cart. She feels that the medication helps her with balance, and that changing the medication could cause her to lose this effect. Alison is aware that her symptom of paranoia may not be as well-controlled on her current lower dose of medication. She feels she may need more medication to prevent another "breakdown." However, she does not want to be "like a zombie" either. Therefore, she is afraid to adjust the dosage in either direction.

The other interesting finding within this sub-theme, was that fear did not necessarily center on medication, but also relative to other ways of managing illness or fear of the unknown. Even if consumers followed medication prescriptions and the "rules of daily living" given by their providers, the illness remained unpredictable.

Dan experienced fear as an infiltrating extension into daily occupations such as work and socialization. He noted that an environmental influence, his physician, played a role in this fear (whether the physician was aware of this or not is not known). Under the recommendation to engage in life activities as much as he could, Dan tried to follow the plan "to the letter of the word." He used dramatic language such as "horrified" and "terrified" as he revealed his fear of not having a schedule, working, and socializing with other people. This must have been particularly exhausting as he tried to follow the schedule of any typical thirty-three year old man, as he indicated. All the while, his symptoms were not in complete remission since his last relapse.

Sean did not demonstrate much in the way of fear per se, but he was so uncomfortable about the side effect of weight gain that one could imagine him feeling afraid. After all, he was trying to work with his physician to lower the dosage of his medication in hopes of lessening this side effect, but unfortunately did not have success with this strategy. Still, this emotion could probably be seen as more of a disappointment than fear. If Sean was indeed afraid of gaining weight, or that he would not lose it, this would be consistent with literature that cites distress or fear of side effects as one of the influences most relevant to non-adherence (Velligan et al., 2009).

In Dan's case, it is apt to wonder how much fear is healthy fear. It is possible that many providers would think that healthy fear of relapse is an indicator that the consumer knows what he or she is up against and will be more self-disciplined in caring for themselves in order to avoid destructive consequences. But it seems there could be a fine line between healthy and detrimental fear, particularly as it relates to performance of meaningful life occupations. It can be akin to living life with severe anxiety, which could potentially be a feature of what Dan and some of the other consumers are experiencing. This level of anxiety is sure to sweep away any enjoyment, no matter how small. The specific features of their illness are not known in these cases, but it is not uncommon for individuals with schizophrenia to struggle with anxiety (Hirsch & Weinberger, 2003; Torrey, 2006).

Since many of the research studies about medication non-adherence focus on reasons and consequences for the problem, the understanding of consumers' lived experiences with medications has not been a large focus (Roe et al., 2009; Zygmunt et al., 2002). It is of benefit to be informed about issues such as fear and insecurity about

medications, even while one is adhering to them. It enlightens the view of consumers' ongoing challenges with medication and helps with the realization that adherence patterns can change in both directions. Their perspectives demonstrate again that medications are imperfect; offering incomplete restoration for those who take them. However, it also demonstrates that this type of fear, thus far, has not led to a decision to stop medication in these four cases. With this in mind, it would be essential for providers to build in non-medication supports to aid in consumers' rest and self-care. After all, illnesses such as these are exhausting to live with.

### **Family Experiences with Consumer Medication Adherence**

In order to triangulate data offered by consumers, this research sought to uncover family experiences with their relative's medication adherence. According to the PEO model (Law et al., 1996), the family is considered part of the consumer's social environment. This is the way in which this research study views the family. However, it is worthy to note that each family member has their own P, E, and O components as they perform the (occupation of) direct or indirect care giving on behalf of their children. This will not be discussed in great detail since families were primarily informing the consumer's perspective in this particular study.

In this research study, each family member had a parent relationship with their son or daughter. Two mothers and two fathers of adult children with schizophrenia or schizoaffective disorder characterized their thoughts about the *absolute necessity of psychiatric medication*. Their rich descriptions of views about their personal family experience emerged through discussion relative to their own beliefs about medication and

illness, consumer adherence and non-adherence rationales, and observations about how medications were seen as effective.

Families shared their own beliefs about medication, particularly as they considered their own illnesses. This was a worthy examination, especially considering the existing literature that families could be a powerful influence in their ill relative's attitudes toward medication (Santone et al., 2008). As stated previously, the findings from this study did not support the notion that families contributed to negative attitudes toward medication as Santone et al. found. They influenced their children, but not in negative ways relative to medication adherence.

Sheila, Dan's mother, lives with depression for which she does not take medication. She did not like side effects when she tried medication in the past, and chooses to manage her illness through lifestyle adaptations. Furthermore, Sheila does not trust medications that she refers to as "chemotherapy drugs." She feels it is shameful that more research is not done with these medications, and that scientific methods are lacking in studies about the effects of medications in this category.

However, given her strong opinions, she believes that Dan absolutely needs medication to manage his illness. She offers her advice to her son, stating that his illness is "just like diabetes" and to take the medication that he obviously needs. Sheila chuckled at herself as she reflected on her advice to Dan, knowing that she does not take medications for depression. Basically, Sheila feels she has the option to choose because her illness is not as severe and life limiting. Dan, on the other hand, does not have a choice.

Maureen has also lived with bouts of depression and anxiety. She reflected on her self-reliance as she learned while growing up in a family of entrepreneurs. She also decided to focus on helping herself feel better by exercising, eating nutritiously, and decreasing alcohol and caffeine intake. She also believes that Rebecca needs medications for her illness, although it did not become apparent that her illness was as severe as it was until fairly recently. In addition to medications, Maureen tries to be influential relative to suggesting ways for Rebecca to manage her weight with nutrition and exercise, in addition to cutting back on alcohol. This will be further discussed in another section regarding family views of social support roles.

Paul lives with multiple sclerosis, for which he takes medications. He struggles with side effects for his own medication, but believes wholeheartedly that Sean should stick with his medications. He shares his experience with medications, the good and the bad, with his son. Paul lets him know that that he sees a noticeable change since he began medications and commented about his faith in Sean.

Richard was non-adherent to medications for his schizophrenia until several years ago. He did not take them for much of his early and middle adult years because they caused too much sedation and cognitive dulling for him to maintain his job as an attorney. When he would spiral downward and illness would overpower him, he would usually require involuntary hospitalization to re-stabilize. He recalled thinking that his medication was horse manure and refused to take the medication when he was discharged. His daughter Alison was well aware of his non-adherence history, as she stepped in as guardian when he was hospitalized. During the years that Richard did not adhere, he wanted his daughter to stay on her medication even though he did not want her

to be hospitalized. Now that he is adherent, Richard still believes that Alison should stay on her medication as well. He is aware that she is bothered by weight gain, but that she needs her medication no matter what.

The beliefs of families regarding medication played a role in their beliefs about their adult child's need for medication, but they did not always rival one another. The belief in medications for oneself did not seem to be necessary in three cases (Sheila, Maureen, Richard) in order to believe in the necessity of medication for their adult children with schizophrenia spectrum disorders. Even when Richard was non-adherent for his own schizophrenia, he believed that his daughter should take hers. He admits that he was not always a help to his daughter, referring to his own period of worsening psychosis. But when he was lucid enough, he knew that medications were essential for her.

In addition to verbalizing their own beliefs about medication, families also expressed their views through reflections on their adult child's rationales for adherence and the act or contemplation of non-adherence to medication. Their reflections were strikingly similar to their adult child's description of personal rationales.

For example, Maureen was well aware of how disturbed Rebecca felt by the disruption in her menstrual cycle. In her view, Rebecca felt she was being sterilized which interfered with her dream of having children in the future. Interestingly, Rebecca went so far as to ask her gynecologist what to do about the medication and its side effect on her cycle. Her daughter reported that the gynecologist suggested that she come off the Risperdal. Unfortunately, this ended up propelling Rebecca into a "super crisis."

Maureen also explained that she knew Rebecca was not feeling better on her Risperdal, and that it was not making her feel good. These descriptions were prominently similar between mother and daughter's interviews.

Sheila rivaled Dan's explanation of taking medication to avoid the terrible experience of psychosis. She explained his incredible fear of not being on medication, exactly as Dan had explained in his interview. She reflected on Dan's ability to decide what is "better for him," suggesting a cost benefit analysis. She also believed that the pill box that he kept in the bathroom helped him to remember to take the medication. Notably, she also expressed the wish that Dan would add an anti-depressant to his regimen to manage his mood disorder, but states that Dan will not take any more medications than he is currently taking. Similar to Sean and Alison, Dan seems to have a perceived boundary for the number of medications that are acceptable to take.

Paul recollected on Sean's non-adherence for the many years of repetitive hospitalizations. He recalls Sean's sarcasm with him about filling the prescription his inpatient psychiatrist had written, "who you getting that for, yourself?" He had always hoped that Sean would decide to take it, but he points out that he never changed his mind even when he had the prescription in hand. Paul's reflection on his rationale for adherence equals Sean's. There was something about his last incarceration and hospitalization that made his son feel that "he's killing himself out there; this is not the way to go." Paul knew there was something different when his son asked him to watch him take the medication. In his view, he understands that Sean does not like the side effects like weight gain and sedation, but he thinks that Sean has realized that he needs the medication "in order to function."

Richard brought up an issue that Alison had not reflected on in her interview. That is, he recalls that she was distressed about not being able to get into the military since she was taking medication for her mental illness. He did cite weight gain as a primary influence in her concern over taking medication. He also explained his own viewpoints about non-adherence to medication to manage his condition. Again, he focused on the side effects from first generation antipsychotic medications that caused extreme sedation and “hampered his capabilities.” He thought the medication was horse manure when he was psychotic. When he finally decided to take the medications since “something told him to take it,” he realized that he was able to get his bills paid and carry his thought processes more easily. This contributed to his adherence in the past few years. He did not complain of side effects such as weight gain.

### **Consumer Experiences with Family as Social Support with Medication Adherence**

Whether or not consumers were hopeful about the future, they expressed a sense of feeling stuck in their world of illness; thus the global theme *wedged between illness and freedom*. This theme emerged despite consumers’ choices to merge medications into their lives. In this way, consumers not only experienced the intense interruption of illness in their life stories, but felt they may be unfruitful in their efforts to live out their lives as they would like. In line with the PEO model (Law et al., 2006); consumers described their experiences with families as part of their social environment. Once again, a transactional relationship was seen between the environment and person components with regards to the occupation of medication adherence.

The obstruction between illness and freedom affected the consumer’s sense of self (P) in their quest for autonomy as young adults, and was perceived to be both helped and

hindered by supportive others such as families and providers (E). So, although the research question initially aimed to understand the family as social support, consumers made it obvious that providers were also major social supports for medication adherence. In addition, the research question centered on how social supports are involved with medication adherence. The findings in this study suggest that, in order to understand this topic, one must explore the more indirect dimensions of social support relationships and life with illness; not just medications.

### **Autonomy and Development**

As is typical in the developmental phase of early adulthood, consumers in this research study desired autonomy in their quest to live their lives separate from their original families (McGoldrick & Carter, 2005). Dan explains in a somewhat bewildering but honest way, how he and his mother “see things differently” and have passive-aggressive interactions “like a parent/kid” relationship. Young adult consumers in this study, not surprisingly, each desired independence for themselves and aspired to progress toward their goals in life. The types of goals and ways they wanted to manage their lives were in line with developmental literature that typifies the phase of life as one of finding meaningful work, settling down in relationships/marriage, starting families, and exhibiting financial freedom (McGoldrick & Carter).

Sean talked about wanting to drive, hold a job, and have relationships in the future. Dan would like to continue his leisure occupation of creative writing. Rebecca would like to get married and have children. They each aspired to set goals for their future relative to how life was for them in the present. They would like to function

“better than they do now” or be “more independent than they are now.” In other words, they are not where they would like to be in their lives, but it does not change their desire to get there or wish they were there.

This is not a departure from the desire of people, ill or not, to achieve something greater than is currently present. However, their goals have certainly been stifled by these challenging illnesses when compared to typical young adults who are establishing close relationships and meaningful careers (Carter & McGoldrick, 2005). As Hirsch and Weinberger (2003) explained, individuals with schizophrenia are disappointed and demoralized about the trajectory of their lives.

The only consumer who did not talk extensively about autonomy was Alison. This is likely because she is living the most autonomously among this group of consumers, married and working full-time. However, Alison did talk about her “next step” in her life as possibly having a baby. However, she is wrestling with the fact that she has such a difficult time taking care of herself that she is uncertain as to whether she can take on the motherhood role. If she does take on this role, she does not like the idea of being a “geriatric mom.” This illustrates her idea of being stuck as she compares herself with other women her age who are likely able to care for themselves and others (McGoldrick & Carter).

The grief over their loss of independence was plain to see. Through their poignant examples of life with illness, they illustrated that taking medications did not erase their losses. Although Sean is functioning better on medication, he has not forgotten about the time he has lost. He feels as though he has been stuck in the same

place for a long time. Dan matter-of-factly illustrates his downward spiral, revealing his loss of friendships, intellect, and educational career in exchange for a chronic illness.

Alison grieves the loss of her former thin self as she deals with her medication side effects. This sheds light on the challenges that individuals face to rebuild lives of meaning as the recovery model suggests (Deegan, 2005). It is awfully difficult to be empowered in life when the loss of control over one's weight is so prominent. Not only is mental illness stigmatizing for these consumers, but also the added hardship of obesity that carries shame through judgment of oneself and by others.

### **Views of Unsupportive Family Relationships**

Internal desires of consumers are helpful as a prerequisite to informing their ideas of social supports. Knowing that they desire autonomy in their young adult lives is the backdrop to their ideas about how they do or do not want their families involved with their medications and health. Their autonomous selves emerged as they brought forth examples of their desire for boundaries in their family relationships. Three out of four consumers (except Sean) discussed their experiences with family as unsupportive. According to the PEO model (Law et al, 2006); unsupportive experiences would be considered a restricted or constrained social environment. Notably, as will be discussed later, they also described examples of supportive experiences with their families.

Rebecca led the group in describing unsupportive experiences with her mother. She brings forth her frustrations with her mother's involvement with her healthcare, as her mother utilized individuals in the profession that she was somehow acquainted with. Rebecca did not want her mother involved with her private meetings with providers as

she desired autonomy in the managing of this area of her life. She viewed her environment as restricting her sense of efficacy. She had relied on providers many years before without her mother's knowledge in order to help her with depressive symptoms and what she thought was ADD. Notably, Rebecca was also bothered by her mother's pressure to lose weight, stating that it caused her to feel guilty and that it does not motivate her to lose weight.

Rebecca also expressed her view that her mother did not acknowledge that she was getting worse on her previous medication, and just wanted her to take it anyway. As Rebecca had explained, "you don't just keep taking something that doesn't work for you." Lefley (1996) states that families could be a symbol of the notion that consumers have not lived up to their family's expectations and that medication rejection could be a way of gaining more control or power. This could have played a role in this consumer-family relationship, considering the pressure she felt by her mother to utilize an "approved provider" and to take medication that Rebecca saw as detrimental.

Dan also expressed views about what he considers to be unsupportive. He reflects back on his relationship with his mother at the beginning of his illness as he used to extensively rely on her. However, later he developed the inclination to manage his life more separately. He was frustrated with his mother's attempt to be involved with his life, as he explained that he wanted to do it on his own to avoid her feeling the need to be "overprotective or make decisions for him." He eloquently pointed out that "practical tips from his mother feels like she's taking care of him" whereas he is more accepting of help from his brother. In the past, Dan has also had to face a far from ideal relationship with his father, who did not believe he needed medications. Furthermore, his father felt

Dan made the decision to take medications just so that he could “identify himself as being mentally ill.” Again, Dan’s environment was perceived by him to be constraining his sense of self.

Alison did not have many unsupportive experiences to share in comparison to Rebecca and Dan. However, she joked about telling her father to “go to hell” when he reminded her to take her medications. In her relationship with her new spouse, she has set boundaries for his involvement in her health. She lightheartedly points out that her husband is “nosey” and wants to “get on the bandwagon” of mental illness. But, she views a role in helping with her health to be “not that great” and would prefer that he does not become overly connected with it.

In typical early adult development, tension between dependence and autonomy is a common experience as he or she transitions away from their parents and into a life of their own (Carter & McGoldrick, 2005). The balance between dependence and autonomy is not static and linear even for typical development. Instead, it is a fragile period of time that contains many steps forward, back and in between. But, individuals with schizophrenia are constantly battling effects of their illness, making it even more challenging to express their autonomy.

### **Views of Supportive Family Relationships**

On the other hand, consumers in this study also verbalized their gratitude for support that they have received from their families. They thanked their families for emotional and material support, which was in line with Breier and Strauss’ (1984) findings that centered on helpful support in consumers’ eyes. Sean, for example, was

grateful to his father for helping him buy furniture for his apartment and helping him to pay his first month's rent and security deposit. So this form of material support was seen as beneficial. Notably, he reflected on his father's support of him by continuing to have expectations of him. This rivals the finding in the Breier and Strauss study that focuses on support in the form of motivation. Individuals in that study defined motivation as the expectation of higher social and occupational function.

Sean also felt that his father accepted him for whom he is despite his illness, which he perceived based on his assessment that his father never changed his behavior toward him. This is an example of what Breier and Strauss (1984) found regarding the importance of social approval and integration. Participants in their study defined this concept as being accepted versus ostracized for the illness. Rebecca explained a similar comment in this research study as she reflected on the importance of her family illustrating that she is a valued person by showing honest interest in what she likes to do. In essence, she wants to know that she matters. As she expressed her views, she did not seem to think that this type of helpful support was happening yet for her. However, she noted that she likes when her family encourages her by noticing improvements. According to the aforementioned study (Brier & Strauss), this would be a type of symptom monitoring, but focusing on noticing her strengths, and not necessarily her difficulties.

Dan was thankful for his mother's emotional support in the form of listening to him and trusting him to make decisions. According to the Breier and Strauss (1984) study, this form of help would be seen as ventilation and problem-solving. He seemed to especially like how she did not say "you're wrong" but listened to him and talked with

him non-judgmentally. Here, one can see his two seemingly disparate views of his relationship with his mother, one that is very supportive and “therapist like” in the beginning years of his illness, and now one in which he desires more separation in his quest for greater autonomy. Interestingly, Dan also benefitted from his relationship with his mother in the form of reality testing (Breier & Strauss).

Alison was also appreciative of her father’s material and emotional support during her crisis period. She states that she owes it to her father for keeping her out of the hospital and protected, allowing her to take time to heal without worrying about the outside world. She reflects on his attempt to create occupational therapy for her by sending her to a pottery class. She humorously states that she loves to buy pottery, but not make it! This relationship between Alison and her father is an excellent example of empathic understanding (Breier & Strauss, 1984). Who would better understand Alison’s needs than a father who also wrestled with a similar set of difficulties?

Three out of four consumers also demonstrated their ability to understand at least some of what their family was experiencing. Rebecca was frustrated with the perceived over-involvement of her mother, but she also believed that her mother was “doing the best she could.” Dan more than noticed his mother’s environment and marriage problems when he worked to protect her from being more stressed by his illness and having a “nervous breakdown.” Sean also reflected on the way his father must have been in a very hard place when he had to put him out of the house due to his bizarre behaviors. His view was reasonable and forgiving as he stated “sometimes you get upset with them, but ultimately they’re related to you.”

Each of these examples brings to light the mixture of joys and hardships in family relationships. This is the case in the “typical” family as well, since individuals are born into a unique family system from the beginning, and are united and bound by history (Carter & McGoldrick, 2005). The hardships associated with mental illness are exaggerated as typical developmental tasks within the family cycle are interrupted.

### **Views of Unsupportive Relationships with Providers**

Consumers in this study brought up an additional topic related to social support; their relationships with healthcare providers. The ways in which consumers saw this vital part of their social environment as restrictive in their quest for illness management, made it an essential topic to examine. The importance of therapeutic alliance is a key feature in the recovery literature and also that of medication adherence (Day et al., 2005; Deegan, 2005; McCann, Clark, & Lu, 2008; Rettenbacher et al., 2004). The consumer perspective reflected the bi-directional nature of the relationship with their providers. The ways in which they experienced non-supportive treatment appeared to affect their self-concept, as will be illustrated through examples from narrative text.

In regards to medication management with their psychiatrists, Rebecca and Dan each expressed frustrations with their unwillingness or poor timing in adjusting medications. Rebecca felt that her doctor must have lacked knowledge in other medications and seemed “lazy” about changing it when she complained of negative side effects. Dan expressed anger as he recalled having “his life turned upside down” with psychotic symptoms. Furthermore, Dan did not feel he had any ability to persuade his doctor to change his medications. This experience is similar to consumers in Roe et al.’s

(2009) study, who found that their providers' attitudes seemed demeaning or indifferent relative to medications.

Alison and Sean revealed their disappointment with providers relative to managing their excessive weight gain due to antipsychotic medication. This particular scenario did not emerge in the initial literature review. Sean found his physician's advice over-simplified when he said "you've got to burn more calories than you're taking in." Alison felt that her psychiatrist did not seem to care, as she did not change her medication and did not give her any "helpful hints." Considering the prominence of weight gain as a side effect, this sort of interaction leaves much to be desired according to these consumers.

Dan described an experience where his doctor was dishonest about side effects of Clozaril. It took his doctor a year before he would admit to the side effect of joint pain. This affected Dan's sense of self as he struggled to understand why his doctor was not willing to divulge this effect with honesty, not to mention living with arthritic pain. He imagined that some "patients with mental illness aren't very honest or as direct" as he is, but Dan looked it up on the computer and he didn't know "how obvious it could be."

In the end, Dan did not feel that he had any control over this situation since he "can't prescribe himself medications," and so he chose to believe him when he said "nope, I don't know anything about that" joint pain. This is in line with the notion of provider in a position of power and the patient as subordinate (Townsend, 2003). Under the medical model, consumers feel disempowered, marginalized, and helpless in the treatment process (Mortenson & Dyck, 2006).

Also a memorable experience was that of being misunderstood by providers, resulting in medication changes that were perceived to be unnecessary. Alison spoke about her psychiatrist's misunderstanding of a situation with colleagues at work for paranoia related to her illness. She reports that this ended up with a medication change that caused her to be "a zombie." Sean recalls a situation with his psychiatrist where he explained his belief that he does not like to take too many medications. His psychiatrist analyzed this to be "nervous or agitated" behavior, and suggested that he add an antidepressant to his regimen. This circumstance was also not seen in the current literature review.

### **Views of Supportive Relationships with Providers**

On the other hand, consumers in this study did have a few positive experiences with their providers regarding medications. Alison and Sean worked with their doctors to decrease dosage for pregnancy and weight loss respectively. Rebecca recalled that the "team approach" at the research hospital helped to boost her confidence in their expertise regarding medication changes. Dan was pleased with a change to a newer generation antipsychotic, even knowing that he had a major relapse at the time of this change (it is unknown how much prominence medication changes played in this relapse).

Since positive experiences were few and far between in this study, consumers reflected on what their ideal experience would be with their healthcare providers. Rebecca would like her provider to use common sense in weighing the side effects with the usefulness of medication. Along the same lines, Alison suggests that providers should "be careful" with what they prescribe. Sean wants his doctors to "come up with something better" so that he does not have to exchange physical health for mental health.

Dan thinks that providers should know their patients well and understand that “small changes can have big impacts.” Not surprisingly based on his experience of provider dishonesty, Dan would appreciate providers being direct, open and up front. He went so far as to say that asking questions “like you’re doing know with these interviews” would be helpful.

In essence, these individuals with mental illness idealize the client-centered treatment process. As demonstrated, their experiences with providers do not, on the whole, line up with client-centered principles articulated in recovery literature inclusive of listening, collaboration, hope, risk-taking, and caring (Clark & Bell, 2000; Deegan, 2006). As the current literature attests to, barriers to client-centered care include the emotional presence of the clinician, readiness to listen to clients’ perspectives, bureaucracy, and beliefs about the abilities of clients to be agents of their health care (Deegan; Fearing, 2000; Mattingly & Fleming, 1994).

Under the PEO model (Law et al., 2006); if more effort was put toward client-centered care, consumers would see their social environment as more supportive and less restrictive, which would in turn help them increase their self confidence in taking care of their health. This change would theoretically improve the fit between P, E, and O components in order to support the performance of medication adherence.

### **Family Roles of Social Support with Medication Adherence**

Families in this study revealed a variety of supportive roles related to medication and illness management. As illustrated in Chapter 4, the process of supporting mentally ill adult children was wrought with complexity and intense emotion as families engaged

in the *puzzling dance of support and separation*. In addition, parents described their impressions of interactions, or lack thereof, with providers. This theme emerged as *the abyss of family-provider discourse*.

Not surprisingly, families described experiences that could be deemed “typical” of families in the life cycle phase of launching children (Blacker, 2005). Although mainstream experiences are illustrated in their narratives, it is apparent that developmental tasks are delayed within the family system. Also, the complexity of developmental tasks is escalated, with higher stakes and the odds seemingly stacked against their adult children with illness. So, atop average and expected parenting issues of young adults, these parents were required to manage other challenging layers of launching their adult children with unpredictable and fragile mental illnesses.

### **Stepping In and Out**

As discussed in the previous chapter, it did not seem to be the case that parents did not want to allow their adult children to discover the world apart from them. It seemed more as if they could not permit this separation to occur in a “natural” way. Based on the literature, it is not unusual for mainstream adult children to return to their parents’ homes after college, thereby causing parents to return to childrearing responsibilities they perhaps thought had passed (Carter & McGoldrick, 2005). However, at least three out of four consumers in this study were not consistently living in an independent setting until they were in their early thirties. This is at least five years later than mainstream adult children who find it necessary to live with their parents after they complete college (Carter & McGoldrick).

Even after they transitioned away from the family home (or away from homeless shelters as in Sean's case), parents continued to be involved in consumers' lives because of their illness. This finding is consistent with Rolland's (2005) Family Systems-Illness Model, which addresses the critical transitions and erratic dynamics of the family cycle within alternating periods of crisis. It is also consistent with literature that illustrates the challenges of separating from adult children with mental illness, and the tendency toward "binding" (Carpentier, 2006; Chrzastowski, 2007; Jungbauer et al., 2004) due to the substantial impact of these illnesses.

### **Stepping in.**

The concept of stepping in and out is similar to language used by Rose (1998) in her study on family relations in mental illness. Rose's qualitative study found that families discovered meanings associated with care giving by stepping back or stepping in, among other ways. Interestingly, the study revealed that meanings were not constant but changed over time. The families in the current study also stepped in and out of the consumer's life, sometimes by invitation and sometimes out of necessity.

Relative to medication management, families in this study did not participate in extensive practical roles on an ongoing basis such as physically giving their adult children medication. Maureen identified a period of time where she did this for Rebecca when she felt she could not manage it on her own, and subsequently learned that Rebecca was hiding and "cheeking" medications. Sheila recalls being more involved in the beginning with logging Dan's medications and studying literature. She also helped him with managing his pill box in the past, but this is not something that she continued to do as Dan became successful at doing this independently. This level of involvement,

particularly at the beginning, is consistent with findings that families are involved in particular, early in the illness course and less so as time passes (Carpentier, 2006).

As a rule, parents in this study took on a much larger emotional role regarding illness management and adherence. This indicates that their involvement did not come to an end, but they remained an emotional support for their adult children. This finding is also consistent with literature stating that families are still highly involved with their time, financial support, and social support even when children live separately from them (Lefley, 1996). The rich descriptions given by parents in this study indicate that their emotional roles were perhaps more taxing than practical roles ever had been.

Consider Maureen's experience of gaining access to an expensive dissolvable antipsychotic medication for her daughter to ensure that she would not have an opportunity to discard it. She vividly described how her plan fell apart before her eyes as Rebecca refused to take the medication she so badly needed. Richard, knowing well his own past experience with non-adherence, reminded Alison to remember her medication because he wanted to protect her from the inevitable downward spiral into psychosis. Paul poured his heart into sharing his own experiences with his son, knowing that Sean was disgusted with side effects from his medication. He wanted his son to know that he also does not like the side effects of his medication, but that he would be in a worse situation without it.

Much of parents' emotional support in this study was indirectly linked to medication adherence. Rather, their support was more associated with the ongoing management of illness. As Rolland (2005) states, the family life cycle includes phases of

illness including crisis periods and the “long haul” that must be journeyed. Both crises and long, arduous journeys were evident in parents’ narratives. Furthermore, families worked to sustain family life amidst the unpredictable course of the illness (Lefley, 1996).

Consider Paul’s effort to bring his homeless son to his house for an assessment by a mental health worker, only for it to end in his son’s bizarre accusations and refusal to accept help. The stakes were indeed high, as Paul considered the danger his son faced every day on the streets and in shelters. He cried as he recalled times when, after a tiring search for his son, he discovered that he was safe. Even though Sean has finally accepted treatment, Paul knows that “there are no guarantees.”

Sheila’s emotional role was apparent in Dan’s journey with illness, particularly so because he could not gain support from his father, who disagreed with his decision to take medications. From early on, Sheila became informed about aspects of Dan’s medication and illness, sharing knowledge with her son to help him make difficult decisions about his care. She was Dan’s confidant in times when he experienced psychosis and utilized her as a reality check. Sheila learned to understand and apply strategies to reduce her son’s stress level. When Dan was grandiose, she resisted telling him that he could not accomplish what he was setting out to do, explaining how challenging it was to know his plan was beyond his ability: “And yet how do you tell your son, oh no, don’t aim for that, it’s too much?”

Maureen endured emotional strain as she tried desperately to get Rebecca to her doctor’s office, knowing she had not been taking her medication. When her daughter’s

psychosis reached a breaking point, she slapped Maureen and ran off. This scenario is supported in the literature as parents become the scapegoat for consumers' resentment, sometimes ending in acts of physical or verbal acts of rage (Estroff et al., 1994). Maureen's first response was "Rebecca, don't do that, you're going to die here!" One can sense her urgent need to protect her daughter, in addition to probably feeling shocked after she was hit. Knowing that her daughter tended toward delusions involving strangers, Maureen feared for her daughter's life.

Richard, although living with schizophrenia himself, worked tirelessly to support Alison during her crisis period by taking leave from his job to sit with her and keep her safe. He also arranged to have his son take shifts of watching her so that she would never be alone. When she was well enough to go out of the house, he encouraged her to go to a pottery class to mimic occupational therapy treatments that he had in the hospital. Although he did not want his daughter exposed to the hospital life, he had recalled that occupational therapy was one experience that was not scary there. Knowing his own experience, he tried to pass on something that he felt may help her start to heal without added stress. (Of course, what he did not know was that Alison would much rather buy pottery than make it!)

### **Stepping out.**

As much as the parents stepped into their adult children's lives, they sometimes felt unwelcome to do so or were left no other choice but to step out. As time went on, Sheila discovered that Dan no longer wanted to depend on her, but instead on his providers. Although she admits that this has given her a new freedom, she also wrestles with her feelings about it. Once again, this is consistent with literature on the difficulty

of family separation in mental illness (Carpentier, 2006; Jungbauer et al., 2004). Dan keeps many of his problems to himself, or talks to his therapist or his brother about them. This challenge extends into daily life, such as wondering whether she has “overstepped her number of visits” with her son. Sheila states that she does not want Dan to feel as if “this tremendous burden is only on him.”

Paul had to make the ultimate decision to step out of Sean’s life by allowing him to live on the streets. His narrative indicates that he felt there was no other option for him. His own environment had changed with the addition of a wife-to-be, and the pressures of Sean’s unstable behaviors were more than he could bear. As he said, “he was sick and America, the planet, everybody was against him in his mind.”

Maureen went through many erratic emotions about whether and how to let go of Rebecca. Already, they had a rocky history together as Maureen had always thought Rebecca required more support than her other children. Maureen commented that she felt she could never please her daughter, no matter what she bought for her. This, in itself, is probably not very different from mainstream parenting. But, in this case, Rebecca’s mental illness seemed to be brewing from the beginning.

More than once, Maureen tried to do what many parents who ascribe to “tough love” principles would do to teach their adult children to handle life obstacles. Although her husband was hesitant, Maureen was adamant that Rebecca needed to go to college and learn to live on her own: “it would be the best thing for her and for us.” But even physical space did not teach Rebecca to learn this for herself. Inevitably, calls would end

up coming in the middle of the night to validate her husband's initial theory that their daughter would not be alright on her own.

### **Guilt and isolation.**

Parents in this study revealed their powerful emotions related to their supportive roles in the lives of their children with mental illness. They lived with guilt about past decisions, their own battles with illness or addiction, or their broken family relationships. They often felt alone in their quest to help their children within their capacity. This finding rivals current literature that highlights the burden that ensues as a result of being called to step up unexpectedly to handle care giving tasks (Carpentier, 2006; Casey, 2007; Lefley, 1998) amidst the unpredictable course of chronic mental illness.

### **Culture.**

Families in this study illustrated that cultural experiences, including generational beliefs, ethnicity, and family customs had an impact on the way they viewed medications and mental illness. This finding is consistent with literature that cites culture as influential in determining how families perceive role expectations and make decisions (Carter & McGoldrick, 2005; Hines et al., 2005; Lefley, 1998).

Each family presented examples of how culture influenced their experiences with parenting a child with mental illness. Maureen reflected on her family's African-American heritage, linking culture to taboo beliefs about mental illness, using psychiatrists, and medication. Although mental illness was experienced by her family, as evidenced by Uncle Buddy's strange behaviors and his need to live with them, it was swept under the rug. Later, Maureen's brother would manifest severe mental illness before she discovered that her daughter suffered with it as well.

Partly due to her culture and upbringing, Maureen stated that she approached problems in search of a solution in a direct and forthright fashion. Just like her family taught her, “something’s wrong, you fix it and you move on...and nothing’s really, really wrong!” In addition, Maureen admits that her personality has never been such that she enjoyed listening to other people’s problems. Dealing with the complexities of this illness would be easy for no one, but this brings to light how differing personalities may wrestle all the more with its impact on the family system.

The literature reveals that African-American cultures tend to utilize an extended family system and place more emphasis on nonfamily supports (Hines et al., 2005). This could explain why Maureen chose to utilize friends as doctors for her daughter. Also, seeing friends that are psychiatrists and therapists could have been away to protect her daughter’s privacy, since Maureen grew up believing that records held by psychiatrists could “mess you up in life.”

Paul, also an African-American, was exposed to similar generational beliefs as he provides examples his ex-wife’s family’s viewpoints. Sean’s grandmother lives with schizophrenia, which was known by everyone in the family, namely Sean’s mother and her siblings who endured a chaotic upbringing. However, Paul perceives that his ex-wife’s family minimized their son’s illness because they did not want to believe that something serious was wrong. He feels that they denied his illness for many years because this would reflect poorly on them.

Sean’s family was not the only family to experience denial. Dan, from a Caucasian family, had a father who was in denial according to Sheila. She revealed

details about his paternal history of mental illness, including a paternal great uncle who had schizophrenia and committed suicide, and two paternal great aunts who were institutionalized their entire lives. Yet, his father did not accept that Dan had schizoaffective disorder, let alone believe in the need for medications.

Richard, a Caucasian man, also came from a generational era that did not believe in mental illness. In fact, he recalls his father working in the insurance business and denying claims based on “traumatic neuroses.” Interestingly, Richard has also been influenced by the mental illness culture itself after having lived with it his entire adult life. Because he is well-versed in this culture, he has learned that hospitals are scary and one cannot trust psychiatrists. On the other hand, his newfound adherence and belief in the need for medication for his daughter have not followed his cultural “training” in a linear fashion. It seems that his cultural experiences are complexly intertwined with the self.

### **Family Views of Experiences with Providers**

Parents in this study described their sense of being excluded from their adult children’s healthcare, with the exception of Richard. Again, Richard had a unique point of view as a consumer of mental health care and a parent. But three out of four parents would have preferred more positive interaction, or any form of interaction is some instances, with doctors and medical team members. This is consistent with literature indicating that families desire partnerships and need to be recognized and valued by providers (Pejlert, 2001; Wilkinson & McAndrew, 2008).

In Maureen's case, Rebecca would often withhold permission for her parents to be involved with her care. When Maureen did have the rare opportunity to speak with the doctor or therapist, she realized how little they knew about her daughter. She wondered why he did not speak to her sooner, and how he would ever expect to make progress with Rebecca's treatment without asking for feedback from those who live with her every day.

Notably, Maureen was also bothered by the discrepancy in doctors' instructions about alcohol use while taking antipsychotic medication. She felt that her daughter took the suggestion that one can have one glass of wine "to the bank." She also rivaled Rebecca's concern over the side effect of disturbed menstruation, but thought the doctor's response to the issue was nonsensical. She implied that this type of response from her doctor contributed to Rebecca's lack of confidence in the medication, ultimately adding to her reasons for not taking it.

Of all the families interviewed, Maureen may have been judged for "high expressed emotion" according to criteria because of her desire to be involved and influential (Rudge & Morse, 2004). Besides privacy regulations, one wonders if perhaps less attention was paid to her based on a pre-conceived notion that she or the family were high EE, and therefore it would be healthier for the consumer to associate less with them. If she was seen as critical by providers, she did not mention this in her interview. However, it is apt to note that Maureen has only recently learned of the severity of her daughter's illness and its impact on her life. In addition, Maureen's upbringing and character have focused heavily on the value of employment. She is in the beginning stages of learning about Rebecca's abilities in the area of work and is likely still grieving

her losses. So, if judgment was bestowed on her for being “high EE,” it would seem unjust in light of providers’ lack of knowledge about her as a person, much less who she is as a mother.

Like Maureen, Paul also wondered why Sean’s providers did not become involved with him or any family member. During an informal conversation with a therapist, Paul discovered that he was being treated for social anxiety instead of schizophrenia. Paul made the same point about the need for providers to connect with those that live around the consumer. He argued that consumers may not be able to say what is happening.

Dan’s providers told Sheila to “back off” of her son and allow him to be more independent. Although Sheila ended up following this instruction, and in ways feels freer because of it, she also wonders if Dan is left to manage too much burden on his own. This also causes her angst over whether she is asking for too much of his time or seeing him too much during the week, as mentioned previously. One of her biggest complaints, though, is about how healthcare providers do not communicate with one another. The person who prescribes the medication does not know details like the therapist knows. She argued that medication appointments are too short to manage care effectively. She was also the primary person to allude to the difficulties around insurance, particularly as it affected her son’s continuity of care.

As discussed, Richard did not have experiences with Alison’s providers per se. But he had plenty of his own in the course of living with illness. He expressed a strong opinion about psychiatrists being out for money and not helping people. He recalled a

doctor coming to see him in the hospital with two aides, one on each side. He perceived this as confrontational rather than helpful. Most striking in his interview was his interaction with one female psychiatrist who he perceived to berate him by saying “now look at you, you’re a lawyer! What’s all of this?” He stated that he would have liked for someone to care about him, and let him know that his care was “uppermost in their thoughts.” He felt that someone could have simply said that the medication would not cause harm and it was not horse manure.

### **Consumer Views of Recovery & Medication Adherence**

The four consumers in this study revealed their ideas about recovery within the global theme of being *wedged between illness and freedom* (Figure 14). Consistent with ideas within the recovery model (Anthony, 1993), consumers indeed expressed hope and progress at times during their interviews. However, the most common experience among these consumers was the sense of liminality in their lives. In this study, liminality referred to the consumers’ sense of being in an overwhelming transitional state much of the time. This is consistent with the dictionary version of liminality which is defined as the condition of being on the threshold or at the beginning of a process ([www.dictionary.reference.com](http://www.dictionary.reference.com)).

It seems that daily existence in the world felt like hard work most of the time, focused very much on the management of their illness, including medication management. This finding is in line with literature that describes consumers’ daily struggles and poorer quality of life related to schizophrenia (Cara & MaCrae, 2005; Hirsch & Weinberger, 2003; Torrey, 2006). Crossing the threshold can be exciting in life, but hovering over the same threshold is hardly hopeful. Because their recovery

experiences were liminal, they always seemed to be on the verge of something, but not able to step over the doorsill to get there. The relief of finally getting there was not a part of their experiences in life with illness.

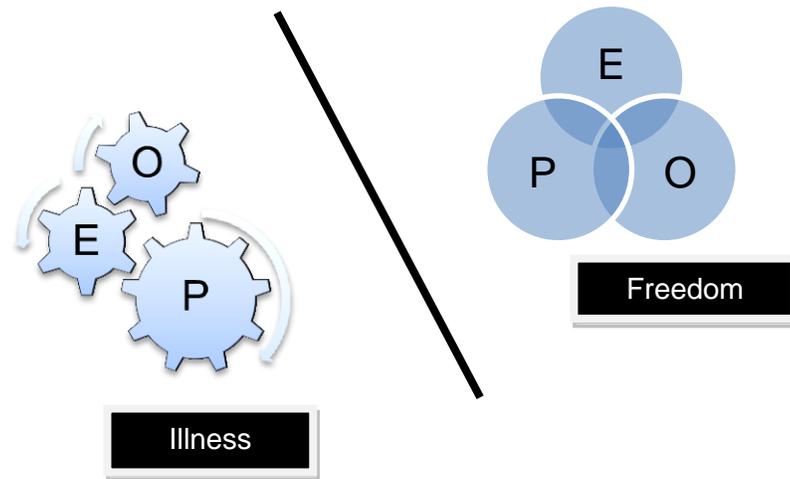


Figure 14: Wedged Between Illness and Freedom

This figure illustrates the overwhelming effects of illness on the person component as the individual learns to live with a serious mental illness. In comparison, a healthy fit between P, E and O is seen as freedom, which is barricaded from individuals who are stuck betwixt and between.

In accordance with the PEO model (Law et al., 1996), substantial difficulties that accompany schizophrenia or schizoaffective disorder affect the person component so significantly that the “P” grows larger (and rapidly particularly in crisis), than do the “E” or “O” components (*Figure 14*). Because the illness wreaks havoc on person’s sense of self and perception of events and others in their environment, they naturally seem to be self-involved. As with the consumers in this study, much energy is spent on daily survival with few opportunities for enjoyment.

Occupations that one would tie to meaningfulness such as work, socializing, or playing music were extensions of the illness management process for these consumers. It was not that they did not aspire for more in their lives, but it was more that they felt stuck *betwixt and between*. Again, the liminality of recovery was evident as they lingered on the threshold.

Consumers in this study engaged in life activities as if they were equal to health activities. The meaning they applied to occupations such as work and leisure represented the search for equilibrium in their health, or the intense need to obey doctor's orders for fear that not doing these activities could lead to relapse. This seems to be different than finding meaning and value in the work that we do or socializing with those that are close to us. For these consumers, health and the management of health was in the forefront. When a person is healthy, balance in meaningful activities is a part of one's experience or at least seems as if it is within reach. The reader is referred to Figure 15 to illustrate the disparity between activities of medication adherence and participation in meaningful life occupations.

Self-care for these consumers, wholly inclusive of illness management, was the primary occupation in their lives. Working, which is normally considered a productive activity according to the Occupational Therapy Practice Framework (AOTA, 2008), seems to be a better example of an extension of self-care in this study. Dan's experience comes to mind especially as he talks about why he works and the ways in which he has had to adapt this activity as a constructive response to effects of illness.

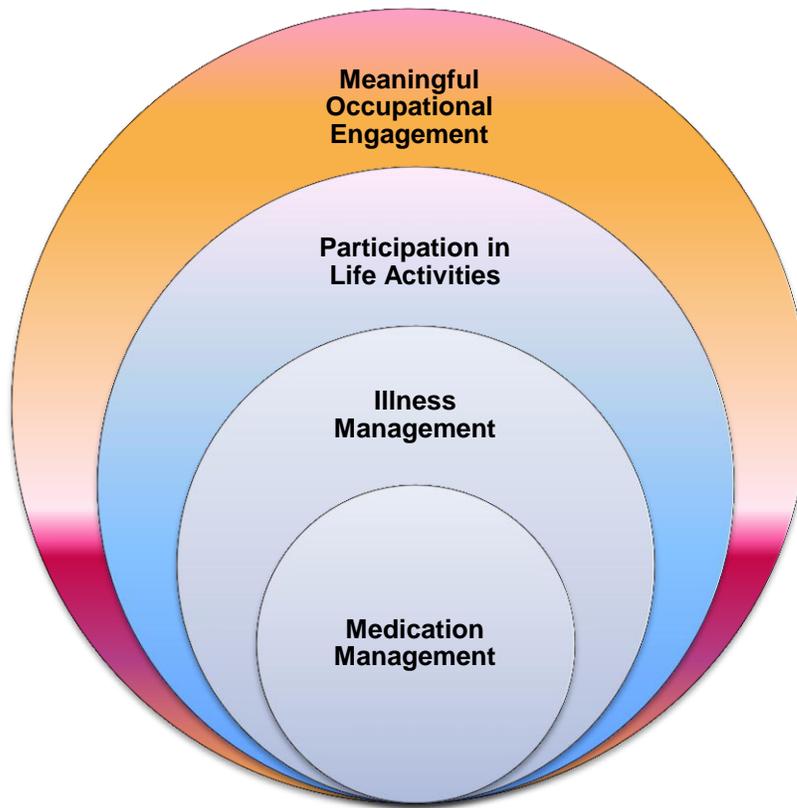


Figure 15: Relationship between Medication Management and Occupational Engagement. This figure illustrates the extreme distance between managing medications and engagement in meaningful life occupations. Participation in life activities is more representative of self-care for survival for consumers in this study.

This brings to light how performing occupations while one is living with a chronic health condition like schizophrenia could hold altering meanings for individuals. It seems that many steps occur amidst the taking of medication and meaningful occupational engagement. Of course we know that whether we are ill or not, unique individuals attribute varying meanings to occupations and that occupations play a key role in constructing lives of meaning (Christiansen, 1999).

So, there is a part of this equation that is not such a departure from life in general. In reality, the perfect PEO fit is probably not the case even for individuals who are not battling a chronic mental illness. Balance may, in a sense, be easier to gain with the presence of health, but it is not within the same reach for every person no matter the health condition. And, if the ideal balance somehow does occur, the PEO fit is sure to change in time since the relationship is not only transactional, but dynamic (Law et al., 1996).

On the other hand, there are parts of consumer narrative interviews that are in line with recovery views expressed in current literature. Consumers in this study expressed snippets of hope and empowerment within their interviews, as supported by the recovery model (Anthony, 1993). They also talked extensively about social supports in their lives, including families and providers. Although they expressed difficulties with social supports, they all expressed notions of needing support in order to live their lives. This idea of social support as a helpful part of recovery is well-supported in the current literature (Schon, Denhov, & Topor, 2009).

In terms of their opinions relative to medication and recovery, each of these consumers admitted to a role of medications in their life with mental illness. Even if they did not seem to embrace “recovery” language in the same way, medications seemed to be a part of managing their illnesses. For Sean, medications were not as important as housing, so they were seen as one strategy among many others in managing his illness. Alison, though she expressed ambivalent feelings toward medication, explained her process of coming to accept medications as part of her “job to take care of herself.”

Interestingly, Alison was the only consumer to express discomfort with taking medications on one item within the Mental Health Recovery Measure (MHRM).

So, the findings in the current study seem to differ with Ng et al.'s (2008) study with Chinese consumers with schizophrenia who expressed that recovery could not be achieved until they stopped medications. None of the consumers in this study alluded to stopping their medications in order to "recover." In fact, it could be said that these consumers took medication in spite of lack of recovery. They also took medication in spite of challenging side effects.

It is apparent that the "wedge between illness and freedom" is present and palpable by all consumers in this study in varying ways. Their experiences contained some hope that if they took medication their lives would improve. However, they had to tread lightly on hope as they experienced disappointment far more than success. In this way, consumers presented more barriers than positive feelings about their ability to move on with their lives with illness. The Mental Health Recovery Measure's (MHRM) "overcoming stuckness" subscale was most suggestive of the theme of "wedged between illness and freedom" that emerged for consumers in this study.

According to narrative data and results on the MHRM, each consumer spoke to the feeling of "stuckness" in their world of illness, using differing vocabulary but describing the same concept. Dan scored lowest in the MHRM subscale regarding "overcoming stuckness." Lower scores point to a less positive view of his ability to move forward. This seems to be in line with his narrative interview, as he explains his lack of possibilities in life with mental illness. He discussed his sense of being tied to his

current geographic location because of his reliance on his current set of medical providers, including the need to manage his medication regimen and other illness management therapies. He knew inside that he would never be a “[Bill] Gates” or “rule the world.”

In fact, consumers provided many examples of how they are working hard to simply survive on a daily basis. Sean stated in his narrative that he was “just managing” in his life, wishing for medications to come along that did not cause weight gain. His scores on the MHRM “overcoming stuckness” subscale also seemed to be in line with his narrative interview, scoring second lowest. Alison stated that she was “hanging on until something better comes along.”

So, although Alison scored equally to Rebecca in the area of “overcoming stuckness,” it appears that her narrative interview results differ. In her case, this may be due to the difficulties presented with impulsivity and ambivalent thought processes. Alison used the narrative interview to explain her conflicting feelings about her illness and medication adherence. For example, she described her pain around the expectation to take medication to be normal “like everyone else,” while simultaneously feeling grateful for the effectiveness of medication that her mother did not have when she committed suicide.

Rebecca, by far, was a consumer that felt most positive about her future. She explained that she may not have schizophrenia forever, implying that she may expect to be cured. In fact, she tied Alison for highest score on the MHRM subscale component, “overcoming stuckness.” Her higher score is interpreted to mean that she views her

ability to overcome stuckness in more positive ways. Interestingly, she scored equally to Dan in the Recovery Attitudes Questionnaire (RAQ-21) factors that allude to beliefs that “recovery is possible and needs faith” and “recovery is difficult and differs among people.” Considering their differing perspectives about recovery, one would expect that their general beliefs on the survey would also demonstrate disparities from one another.

Notably, consumers also expressed the difficulties of living with stigma around mental illness. Stigma and its negative effects are well documented in the current literature (Cara & MaCrae, 2005; Corrigan, Larson, & Rusch, 2009; Torrey, 2006). Issues that emerged as part of consumers’ personal experiences in this study include stigma against homeless persons, media portrayals of individuals with schizophrenia as violent, and stigma regarding obesity as a result of medication side effects.

Alison, in particular, expressed her sense of pressure by society to take medication. She eloquently revealed her experience of feeling the need to take medication because “it’s what everybody wants.” In addition, relative to medications, Rebecca expressed an interesting point about media and the positive effect it seemed to have on her impression of Abilify, an antipsychotic medication. She clearly recalled how Abilify is also used for depression according to the television advertisement. This seems to be a form of self-stigma (Corrigan, Larson, & Rusch, 2009) toward having a thought disorder versus mood disorder, which is presented in the advertisement as a more socially acceptable diagnosis.

When the recovery model is considered within the context of consumers’ data from this study, it was most apparent that consumer’s expressions of concepts of recovery

such as self-agency, hope, resilience, active involvement with treatment, managing daily life, following dreams, and pursuing meaningful goals (Deegan, 2005; Lieberman et al., 2008; Noh, Choe, & Yang, 2008) were mixed. While consumers reflected on their experiences of developing self-agency for health management and the desire for active versus passive collaboration with their providers, they did not speak directly to concepts such as hope, resilience, and following dreams (Anthony, 1993). Some consumers wished for a cure for their illness, even if they thought it was unrealistic. As Sean and Dan said, “a cure would be great.”

Concerning the concept of “recovery from” versus “recovery in” illness as described by Davidson and Roe (2007), consumers in this study were only minimally aligned with this viewpoint. Most consumers did not believe in the requirement of a cure from illness (although Rebecca did in fact believe this is possible for her). But at the same time they did not altogether live their lives with less attention to the impact of their illness. As discussed previously, these consumers had to spend most of their energy and time managing their illness, and much less time on the performance of meaningful occupations. With this information in mind, this seems to be suggestive of Torrey’s (2006) concern over placing too many expectations on individuals to recover, which could increase stress for them as they attempt to live with serious illness symptoms.

### **Family Views of Consumers’ Recovery and Medication Adherence**

Families in this study expressed views about medications and recovery, alongside and embedded within their general beliefs about recovery for their mentally ill adult children. Their data suggests that *recovery is more than what meets the eye*. As previously discussed, parents in this study each felt that their adult children absolutely

needed medications. This section ties this perception for absolute need for medications with their beliefs about mental health recovery for their children.

Sheila and Maureen shared their skepticism about recovery for their children. This is not to say that they did not agree with any of its principles. But all in all, they looked at their children's chronic difficulties and wondered whether the positive language in recovery has much to say about their circumstances. Both of these parents believe that medications have helped their children based on what they observe. However, she points out the unpredictability that her son and the family face each day, and the real possibility (and experience) of relapsing even while taking medication. She reflects on the chronic nature of schizophrenia, how it will be a problem forever and the perception that her son just has to "deal with it" since there does not seem to be a combination of drugs that will make it any easier for him.

Maureen "tries to tell herself" that the reason her daughter is so "chipper," even while not being able to follow through with meaningful employment, is perhaps because her medication is helping her. At the same time, she views her daughter's large chunks of unstructured time to be an example of her "slipping" in her recovery. Because Maureen holds the generational family value of employment so tightly, she illustrates her disconnection with Rebecca's seemingly happy-go-lucky attitude. Both Sheila and Maureen's view of medications and recovery are in line with Rose's (1998) study that explained how some families may accept the person with illness, while others continue to question whether anything positive remains.

It is obvious from her interview that Sheila accepts Dan as a person with illness, but grieves his difficulties simultaneously. Maureen wants to accept her daughter's illness, but it is not easy for her. One can imagine her internal struggle with wanting Rebecca to be "chipper" about life, but wondering how in the world she could be if she is unable to engage in meaningful productive life. In particular, Maureen's data is in line with documented issues that the family may face when they question their loved one's capability in doing what is necessary for recovery (Lefley, 1997).

As for Paul and Richard, they expressed more tempered realism and positive views of recovery. They also believed in the support of medications for their adult children. Paul believes that one can still have symptoms of mental illness and be in recovery. He likens Sean's recovery to his own experience of recovery from alcoholism, believing that Sean will have to maintain his level of recovery by doing the "same stuff that made him well" including keeping a consistent schedule, staying in touch with family and friends, and maintaining use of the right medication. Richard believes that recovery for Alison is possible in her current life situation with a new husband and in-laws for support. For himself, he believes in the power of faith in God and prays for both of his children who live with mental illness.

Interestingly, although Paul expressed such positive points of view within his narrative, he scored lowest, at 75%, on the Recovery Attitudes Questionnaire (RAQ-21), indicating that he felt the least positive of all the families about mental health recovery. Richard, on the other hand, scored highest (88%) on the RAQ-21, which is consistent with his narrative views on recovery. Important to note though, is that each family member scored higher on the factor "recovery is possible and needs faith" than the

second factor “recovery is difficult and differs among people.” This can be interpreted in a way that parents feel recovery is more possible than difficult. Consumers expressed this same belief that recovery is more possible than difficult.

As a comparison of attitudes between consumers and families on the Recovery Attitudes Questionnaire (RAQ-21), consumer-family dyads 1 and 2 scored similarly with one another. More discrepant viewpoints were illustrated in consumer-family dyads 3 and 4. Consumer 3, Sean, had more positive views of recovery than his father. On the other hand, Family 4, Richard, had more positive views of recovery than his daughter. Sean and Paul’s RAQ-21 scores did not seem to mesh with many of their narrative ideas. If one were to just look at the RAQ-21 scores without considering the narrative data, it could be assumed that Sean and his father views could affect the nature of their relationship. However, the narrative data illustrated perhaps the most stable and comfortable parent-adult child relationship between Sean and Paul. Conversely, Alison and Richard’s RAQ-21 scores did seem to match their narrative data in the presence of discrepant viewpoints within both forms of data.

### **Research Limitations**

The number of participants in this study was limited, so findings are not able to be generalized. However, this study sought in-depth versus cursory experiences about medication adherence, social support, and recovery. Clearly a more qualitative endeavor, it was not the aim of this study to generalize findings.

Through the process of recruitment of consumers and families in the community, many lessons were learned. First, for consumers who live with schizophrenia spectrum

disorders, recruitment efforts are most fruitful in person. Although it seemed to be a reasonable idea to display fancy flyers and business cards in mental health settings, many individuals with schizophrenia illustrated a need to attain a level of trust with the researcher. Meeting in person permitted the researcher to begin initial trust building with the consumer, which is particularly important given the sensitive topic area of medication adherence.

Second, working with consumers in which a researcher already has an established relationship should not necessarily be interpreted as an advantage. The expectation of working with a consumer and family member that were previously known was that they would be more comfortable and honest about their experiences. Although this was found to be the case for the family interview, it was not the case for the consumer's.

Whether or not the consumer's reluctance to discuss her non-adherence was a result of severity of symptoms or the establishment of a previous relationship is not entirely known. But, for reasons not clear, it took longer to establish trust concerning this topic with Rebecca than any other consumer in this study. This was surprising, but something to be kept in mind for future study recruitment.

### **Instrumentation**

There is no question that qualitative research using multiple case studies and open-ended interviews yielded the rich, in-depth data sought for these multidimensional topics. One of the most significant benefits to using narratives from consumer and family perspectives was to capture the many "gray areas" in their experiences with medication adherence, social support, and recovery. Conflicting feelings about medication, social

support, and recovery were illustrated by all consumers. Interview data encapsulated the participants' non-linear and dynamic processes relative to managing illness, which is supportive of the recovery model.

In addition, the findings in this study indicate that more was learned about recovery without using the professional language of recovery. That is, a deeper view of one's life with illness or as a family member of someone with illness was offered throughout the entire interview process far preceding the introduction of "recovery" as it is currently understood within literature. It was really a compilation of life experiences that permitted a viewpoint of recovery in the sense of moving forward with life despite remaining illness symptoms. In short, this study suggests that the best way to ask these particular individuals about recovery is to inquire about what is meaningful to them in their lives and how they view health for themselves.

Furthermore, the generic script about recovery that was read verbatim to all participants amounted to similar types of responses as forced choice questionnaires. For example, Dan has a half page of transcript devoted to his own impressions of recovery, compared to three word responses following the script about recovery: "that seems true." If quality information about a person's recovery perspectives is desired, it would seem important to withhold unfamiliar terminology that would need to be integrated before it can be truly applied to one's life situation.

Considering what was gained through rich, descriptive narratives, survey data did not add a considerable amount of desirable information in this study. A recovery survey would have never been enough to capture the complexity of these consumers'

thoughts, nor the families for that matter. Choosing “agree or disagree” to whether one hopes for improvement with remaining symptoms is not enough to reveal the complicated areas about how people manage their lives with this illness. It is possible, as indicated in this study, that consumers have hope about some parts of their lives, while continuously grieving the loss of autonomy and the presence of symptoms that treatment has not yet solved for them.

At the same time, adding the surveys as a small part of this study did not seem to detract from the narrative data. Even in the instance where narrative and survey data were discrepant, this offered the researcher an opportunity to reflect on why this may have been the case. This instance is one that can be learned from, as surveys with forced choice answers may provide more information for some participants than others, depending on characteristics of the person. Although narrative data is not as straightforward to “score” as surveys are, this study demonstrates that exhaustive analysis of human experience, as it emerges within their own language, is most suitable to inform this research area.

Finally, adding families as a triangulating perspective was certainly achieved in this study. Their perspectives often validated consumers’ experiences with medication adherence. However, in addition to validating consumers’ experiences from their perspectives, it was learned that families have a wide range of their own intricate, complex experiences. The opening of “Pandora’s Box” was not all that surprising given the knowledge gained within the detailed literature review about families.

Gaining knowledge from the family perspective was one of the most valuable outcomes of this study. But admittedly, it was difficult for this researcher to “stop” at triangulation. In other words, more layers emerged that seemed to suggest that medication adherence extended far beyond practical roles for families. And although emotional roles were expected to transpire to some degree, the depth and complexity of these roles was an unexpected result. Because their perspectives needed to be honored, it became a lengthy process of data analysis for a single researcher to accomplish. This effort was worthwhile and without regret, but it may have been more appropriate in retrospect to divide consumer and family perspectives into two separate studies.

### **Theoretical Models**

The occupational therapy model, PEO (Law et al., 1996) proved useful in this study. It was broad enough to capture aspects of each consumer’s experience in a categorical fashion of person, environment, and occupation. Family members in this study were seen as part of the consumer’s social environment, although components of PEO also could have been applied to family members themselves as they performed the occupation of care giving. However, since this study placed the consumer as the primary case in question, PEO was not applied to families for this particular study.

Support was found in this study for the assumption that the person is always changing, as stated in the PEO model (Law et al., 1996). But, PEO also states that the environment is more conducive to change than the person (Law et al.). When considering findings that emerged from consumers’ perspectives regarding their social environment, including families and providers, this may not be the case. Although it is obvious that illness experience as part of the person seems to be unforgiving and

relentless, one wonders how simple it would be to change the perception of social supports in their lives.

In particular, their illustrations of challenges to being self-agents of their care in relationships with providers depicted the vision of a medical model in full force, not a recovery model. Changing the environment may be more straightforward when considering adaptations to the physical environment. An example that comes to mind is providing a raised toilet seat to help a person with limited strength and mobility manage their toileting needs. But managing a mental illness, inclusive of medication adherence, is not so concrete. Medication adherence, as learned in this study, is rooted in many unseen components of person, environment, and occupation (*Figure 16*). In addition, the mental health delivery system and community at large are influenced by all aspects of the environment, including cultural and economic, as described by PEO.

Also, the PEO model (Law et al., 1996) was helpful when applying knowledge of chronic illness to its components. As examples within consumers' narratives surfaced, it became apparent that "person" components were particularly stressed in comparison to environment and occupation components. This is not to say that the environment or occupation becomes less important. What it illustrates is that much of one's personal energy is so fixed to the management of illness, that freedom to engage meaningfully and freely seems idealistic.

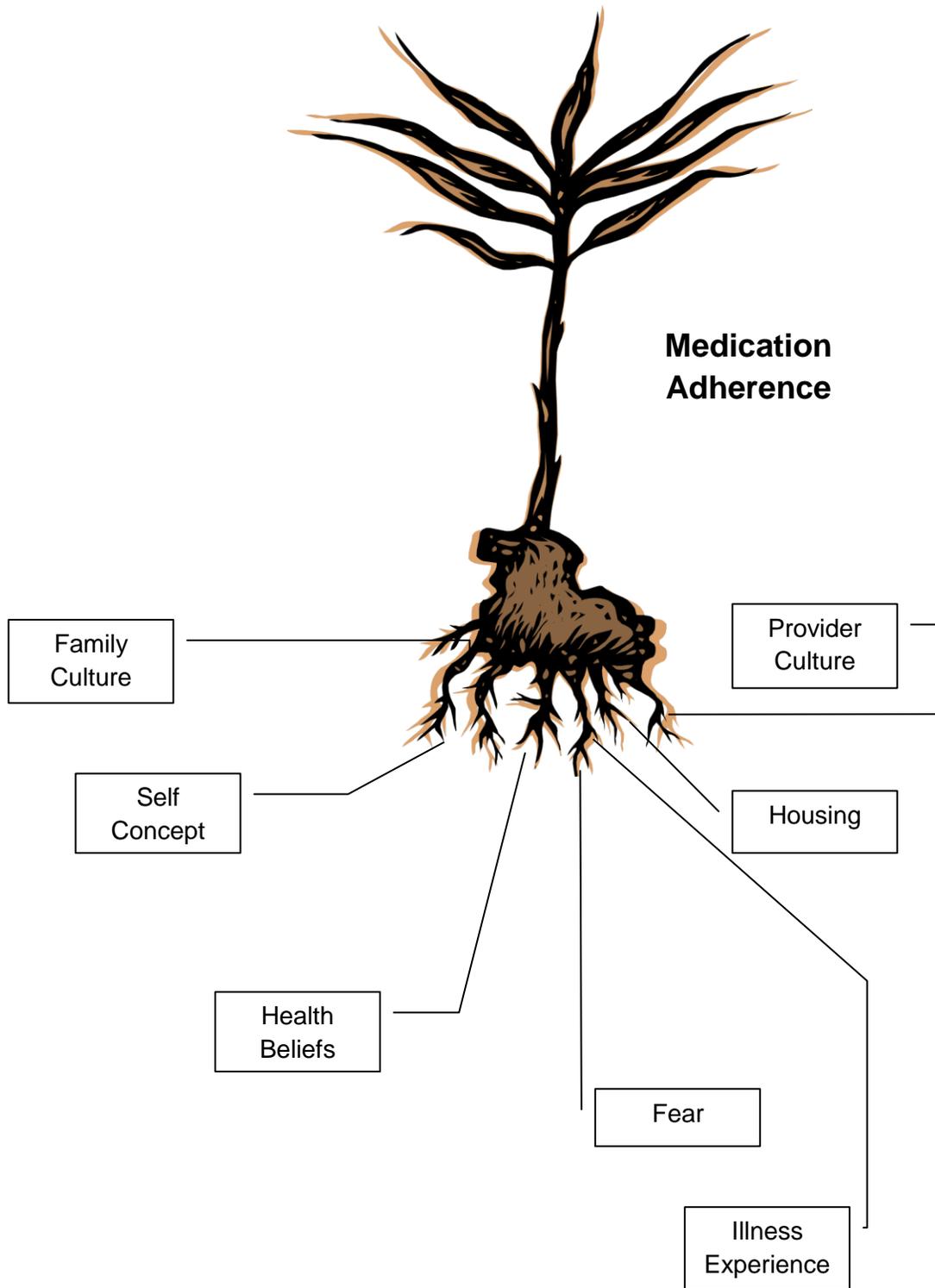


Figure 16: Roots of Medication Adherence

The recovery model (Anthony, 1993) was also useful in highlighting both suffering and successes of individuals living with schizophrenia or schizoaffective disorder. What stood out as so different though, is that greater hardships prevail as much energy is spent keeping the illness at bay. The idea of moving forward with recovery despite remaining symptoms (Anthony; Deegan, 2005; Lieberman et al., 2008; Lysaker & Buck, 2006) did not seem to be the case for most of these consumers as much as being wedged in their world of illness.

Yes, they moved forward in terms of putting one foot in front of the other, but what choice did they have? Consumers' experiences in this study are more reminiscent of daily survival than living life to the fullest amidst illness. Medications, though they determined them to be helpful enough, were imperfect aids to living their lives meaningfully.

Does the recovery model capitalize on the longing on mental health consumers' desires to get better (Torrey, 2006)? One wonders how and why recovering from mental illness is set apart from recovery from other illnesses. Although mental illness admittedly contains unique features that cause distinctive barriers to living, it is conceivable that ideas of recovery could unintentionally contribute to stigma. Is this model more for providers? Consumers may not embrace this model, as seen in the study. Alison's sarcasm captured this point when she responded to the statement about recovery: "Well that sounds nice...sounds like a doctor figured that one out!"

Reflecting on Paul's analogous statements between mental health recovery and alcoholism, one notices that some aspects are similar and some are very different.

Through the twelve steps of recovery, Paul integrated a new perspective and used his support system to rid his life of the deleterious effects of alcohol. This can certainly be similar to aspects of mental health recovery as consumers develop self-awareness while learning to rely on supports in their lives.

As hard as it is to do, individuals recovering from alcoholism likely come to a point where they either acquired new perspectives and/or gained enough support to stay away from the addiction or else tumble into relapse with a simple sip of alcohol. But what choice do consumers with chronic mental illness have? They cannot always choose to keep relapse at arm's length. Medication and social support are often not enough to stop relapse of symptoms. This loss of control was illustrated even with medications on board in this study. The predicament of feeling "stuck" becomes more understandable with this point in mind.

The recovery model (Anthony, 1993) also permitted emphasis of family ideas about medications and recovery for their adult children. A variety of perspectives emerged, including those that were skeptical versus approving. Sheila and Maureen brought forth significant concerns over recovery concepts, including divergent ideas between their children's' desire for autonomy and their parental worry over whether their children are able to handle such a burden alone.

Paul and Richard welcomed ideas of recovery more readily. This was particularly the case for Richard, who has lived with schizophrenia for his entire adult life. This was an interesting finding in this study, particularly in light of Richard's non-adherence to

treatment for so many years. Perhaps his recovery ideas emerged and changed gradually as he discovered how he was to manage his life with the illness.

### **Implications for Occupational Therapy**

Psychiatrists were discussed extensively by consumers and families in this study. In particular, their perceptions of their psychiatric care in many instances leave the reader wondering how the medical system could have gone so wrong in the care of individuals with chronic mental illnesses. However, existing barriers within psychiatric medication management bring to light the significance of other mental health providers who also play roles in helping individuals to live their lives with mental illness.

This certainly includes the work of occupational therapists in treating mental health conditions. It may be a stretch to say that occupational therapists have more time than psychiatrists, but it is more apt to declare that therapists spend their available time uncovering the client's world of meaningful activity amid interruptions that often occur when mental illness crashes in. This understanding can be of extreme utility as the interdisciplinary team and family members work to understand and help the client. Occupational therapists, like other providers, are challenged to examine their practice relative to medication adherence.

Discovering more about the person, their environment, and occupations that reflect the individual's responsibilities, interests, and values can help the occupational therapist gain a holistic view of his or her world. This is not only desirable, but non-negotiable in understanding how he or she perceives medications in the treatment of a health condition. So, occupational therapists absolutely have an essential role in

medication adherence in today's healthcare environment. Though occupational therapists are non-prescribers, this does not denote non-significance.

However, it appears that in the current mental health delivery system, consumers have access to psychiatrists far more readily than occupational therapists. This may be a future research area relative to exploration of occupational therapy involvement at the community level that centers on support for consumers and families who are managing these challenging illnesses.

One of the major findings in this study was that medication adherence was one aspect in a sea of mechanisms that consumers use to manage their illnesses. This observation grew as themes were more deeply understood regarding merger of medications and the experience of being wedged between illness and freedom. As the enormity of the "P" component came to light, it was apparent that consumers had to spend much of their time within. They tried to keep their symptoms at bay by doing what was needed in their daily lives. This included medication taking, but extended into daily occupations such as work and leisure.

Although this finding unearths a major barrier to experiencing meaningful life, it also has an upside. That is, consumers with mental illness in this study were very ardently working toward discovering what they needed, using trial and error, making decisions, and utilizing adaptations. Davidson and Roe (2007) refer to these efforts as the "active work of recovery."

Considering the harsh effects of illness, medication side effects, and environmental influences on consumers' sense of self, it would seem beneficial for social

supports to build consumers up in ways that are dignified. This would support the individual in a way that helps them to live with illness, instead of undermining their efforts.

Knowledge gained in this study about families can also be utilized in the design of more effective mental health service delivery. As family members stated so eloquently, it makes sense to include families in treatment as they know the consumer day in and day out. But, consumers' desire for autonomy in managing their illness in their young adult phase of life needs to also be considered. Balancing this interaction, amid health privacy regulations, seems to be a challenge that requires further study.

One of the most striking areas for discussion based on the results of this study is the lack of long-term comprehensive community-based mental health services that meet individual needs. As implied previously, health providers, including occupational therapists, cannot expect to help clients incorporate medications into their health management regimens during a 48-hour hospital stay or a 10-minute outpatient "med check." It is a sad state of affairs when, as Dan put it, "you do not have to put the car in park" for a hasty medication follow-up with the doctor.

Given limitations in mental health care today, it is especially significant to utilize time with consumers in a way that supports them. Thought disorders as present in those living with schizophrenia can make it particularly challenging to uncover coherent experiences. This makes it all the more necessary to spend the time needed to give the client a voice in their own lives. The problem of medication non-adherence would not be fixed in a day, nor would it be solved by one person. But, as consumers explained in this

study, they are paying attention to verbal and non-verbal interactions with social supports. The fact that consumers in this study utilized trial and error is also significant. This brings to light, as expressed in the recovery model (Anthony, 1993) that consumers with mental illness desire the right to try and fail (or try and succeed) as do others without illness.

If occupational therapists believe that occupation influences health, they have to know that asking about the ways in which consumers live their daily lives with mental illness is an important link to medication experiences. Whether or not the consumer is aware of this link is really not as important as consideration of various components of health management and investigation of fitting ways to facilitate a consumers' ability to live with a chronic illness.

Recovery may be better described by "discovery," as this study suggests. Discovery is part of how human beings, whether ill or healthy, learn to adapt in life. Perhaps this concept is less stigmatizing as it is less illness-focused and more "normalized" in terms of living life in the face of challenges. In reality, the PEO fit for individuals who are healthy is not ideally balanced. In typical everyday life, people experience varying prominence of P, E, or O components. They are certainly in motion since they are dynamic and non-linear.

As occupational therapists help clients to make connections in their discovery of ways to manage illness, it would be helpful for clinicians to reflect on the importance of seeking to understand, and then seeking to be understood (Covey, 2004). Embracing this client-centered orientation demands that clinicians listen openly rather than devising a

persuasive argument prior to understanding the issue at hand. This study has emphasized the depth of medication experiences for consumers and the need for social supports to be informed by those that live it every day.

### **Implications for Future Research**

First and foremost, much was learned in this study about families who often spend a great deal of time with consumers who have schizophrenia. Since families were not a primary focus for this study, future studies about family member roles in medication management would be a valuable addition to the body of knowledge. As stated previously, including families in this study was worthwhile. However, deserved attention toward family members and the multidimensional issues they face would be better focused in a study devoted to them.

Another interesting finding that emerged in this study was the ability of each consumer to express some degree of awareness about their mental illness. Reflecting on this data, it is likely that a combination of multidimensional characteristics may have influenced awareness, including trial and error experiences, time and maturation living with illness, and other mechanisms that humans all use to grow and adapt.

Based on Dan's data, it would seem that he began his illness journey with awareness on board, even during periods of psychosis. He was able to seek help for himself in the midst of internal upheaval, and made difficult decisions about taking medication in spite of conflicting opinions in his family. He continued to exhibit awareness of his illness and took a logical approach to weighing risks and benefits of medications around an axis of intense fear of relapse and medication failure.

For Sean who endured a long period of non-adherence to medications, one may imagine that he wandered the cold streets in dirty clothes, in and out of homeless shelters because he did not realize how ill he really was. Instead, he lived in an imaginary world and woke up only when he was pummeled hard enough to kick start his cycle of incarceration and hospitalization. Though Sean prefers not to remember these times, it is apparent that his father knew how very ill he continued to be when he was lucky enough to find him alive in homeless shelters. Sean himself rivals this by saying “sometimes you as the consumer are the last to know.”

But one day that all seemed to change for Sean. Was returning insight greater for that hospital stay than in previous stays? Or was a different medication used that evoked greater symptom recovery? Or did he finally develop a trusting alliance with a provider during that stay? These questions cannot be answered in this study, but it would be interesting to factor in awareness of illness over time.

Finally, mental health providers emerged as a significant topic of concern for both consumers and families in this study. Since mental health providers did not have a voice in this study, including their perspective in a future endeavor would enrich understanding about medication adherence. For example, more could be learned about providers’ reasons for dishonesty about medication side effects.

### **Conclusion**

The findings of this study indicate that consumers merged medications into their lives as imperfect instruments of self-care. The merger happened at various points in consumers’ illness continuums, and it did not necessarily imply a guarantee for continued

adherence. Consumers also expressed their sense of being wedged between illness and freedom as they became self-focused on managing their illness to the best of their ability. Being wedged had implications for social support involvement and personal viewpoints toward mental health recovery as these young adult consumers worked toward developmental life tasks that have been delayed as a result of chronic mental illness.

Findings from this study suggest that families believe in the absolute necessity for psychiatric medications for their adult children despite their own viewpoints toward medications for themselves. They also described a puzzling dance of support and separation, which brought forth both typical and atypical parent experiences with children in the young adult phase of life. Finally, they rivaled consumers' concerns over interactions with providers as they reflected on the abyss of family-provider discourse in their efforts to support adult children with managing their chronic mental illnesses.

Medication adherence proved to be a multi-layered phenomenon for consumers and families in this study. A favorable view of recovery was not necessary to adhere to medications for these particular consumers. Consumers in this study took medication despite lack of recovery. Nor was a positive view of recovery necessary for parents to believe medications were essential for their adult children. Future studies are suggested to enrich understanding of complex phenomena within these important topic areas.

## Appendix A

**RENEWED APPROVAL NUMBER: 11-A029R1**

To: Susan Krutis  
From: Institutional Review Board for the Protection of Human  
Subjects, Debi Gartland, Chair *D G/WKP*  
Date: Monday, August 29, 2011  
RE: Application for Approval of Research Involving the Use of  
Human Participants

Office of University  
Research Services

Towson University  
8000 York Road  
Towson, MD 21252-0001

t. 410 704-2236  
f. 410 704-4494

Thank you for completing the Annual Review Notice for Projects  
Involving Human Participants for the project titled:

*Medication Adherence, Social Support, and Recovery: Perspectives of  
Consumers with Schizophrenia and their Families*

Since you have indicated that your research project is still active, we are granting you a renewal of your approval. If you should encounter any new risks, reactions, or injuries while conducting your research, please notify the IRB. Should there be substantive changes in your research protocol, you will need to submit another application for approval at that time. This protocol will be reviewed again one year from this date of approval.

We wish you every success in your research project. If you have any questions, please call me at (410) 704-2236.

CC: MB.Merryman , S. Robinson  
File

## Appendix B

WOULD YOU LIKE TO BE PART  
OF AN



IMPORTANT STUDY?

## Medication Experiences

- ✓ ARE YOU AN ADULT CONSUMER WITH SCHIZOPHRENIA OR SCHIZOAFFECTIVE DISORDER BETWEEN THE AGES OF 22-35?
- ✓ ARE YOU A FAMILY MEMBER OF SOMEONE WITH SCHIZOPHRENIA OR SCHIZOAFFECTIVE DISORDER?
  - **DO YOU WANT TO CONFIDENTIALLY SHARE YOUR THOUGHTS ABOUT EXPERIENCES WITH MEDICATIONS, INCLUDING TIMES WHEN A DECISION WAS MADE TO STOP OR CHANGE PRESCRIBED MEDICATION?**

I AM CONDUCTING A STUDY ABOUT MEDICATION EXPERIENCES WITH CONSUMERS AND FAMILY MEMBERS. WHAT HAS IT BEEN LIKE FOR YOU? YOU HAVE LIVED IT, AND YOU ARE THE EXPERTS! THIS STUDY WILL HELP PROVIDERS TO BETTER UNDERSTAND MEDICATION EXPERIENCES AND RECOVERY. FOR MORE INFORMATION, CONTACT:

**Susan Krutis, Occupational Therapist, Principal Investigator**

**E-mail: [SUSANOT@LIVE.COM](mailto:SUSANOT@LIVE.COM)**

**Or Call: 1-443-340-2312 (I will return your call so you will not have to pay long distance)**

Approved by the Towson University Institutional Review Board (IRB) #10-A011R1

Dr. Debi Gartland: [OURS@TOWSON.EDU](mailto:OURS@TOWSON.EDU) OR 410-704-2236

## Appendix C

**Information about Research Study:****Medication Adherence, Social Support, and Recovery: Perspectives of Consumers with Schizophrenia and their Families**

**TO: Potential participants for research study about medication experiences**

**FROM: Susan Krutis, Occupational Therapist and Principal Investigator**

Please consider participating in an important study! I would like to understand what taking medications has been like, including times when you may have decided to stop or change your prescribed medications. I would also like to understand your beliefs about recovery. Criteria for participation include being 22-35 years of age, being diagnosed with schizophrenia or schizoaffective disorder, and being ill for 2 years or more. Also, one family member who has contact with you twice per week must agree to participate as part of this study.

The consumer with schizophrenia or schizoaffective disorder who participates in this study will take part in 2 private, audio-taped interviews about their experiences with medications, including times when the consumer decided to change or stop their prescribed medication. The consumer will also complete 2 brief questionnaires about recovery. The family member who participates will take part in 1 private, audio-taped interview and complete 1 brief questionnaire about recovery. Both the consumer and family member will also participate in a follow-up telephone call to make sure the researcher understood what the participant intended to say.

Participation is voluntary and your confidentiality is assured. This study has been approved by the Institutional Review Board of Towson University.

Thank you to you and your family member for considering participation in this study. Your participation will enhance understanding of taking medications for psychiatric illness, which may help medical providers to better serve people with mental illness.

Please contact me with any concerns or questions about participation in this study:

Susan Krutis, M.S.Ed., OTR/L: Principal Investigator; Doctoral candidate, Towson University; Phone: 443-340-2312; E-mail: [susanot@live.com](mailto:susanot@live.com)

OR

M. Beth Merryman, Ph.D., OTR/L: Associate Professor, Department of Occupational Therapy & Occupational Science, Towson University;

Phone: 410-704-2272; E-mail: [bmerryman@towson.edu](mailto:bmerryman@towson.edu)

OR

Dr. Deborah Gartland.: Chair, Institutional Review Board (IRB), Office of University Research Services, Towson University:

Phone: 410-704-2236; E-mail: [Ours@towson.edu](mailto:Ours@towson.edu)

## Appendix D

### Telephone Screening Protocol

Research Study: Medication Adherence, Social Support, and Recovery: Perspectives of Consumers with Schizophrenia and their Families

Consumer Name: \_\_\_\_\_

Thank you for your interest in this important study. The main purpose of this phone conversation is to briefly describe the study and see if you would like to participate. If you think you would, we will set up a time to meet to begin the study. Please ask any questions that you have as we talk today. Also, I will provide you with my phone number and e-mail address so that you can contact me anytime with questions.

(Explain the main purpose of the study and the methodology, followed by a discussion that includes the following):

1. I would be interested to know more about you, and glad to answer any questions you have. Would you mind telling me how you learned about the study?
2. As I explained earlier, my study involves persons with a diagnosis of schizophrenia or schizoaffective disorder. Does this describe your diagnosis?
3. (If yes to above), how long have you had this diagnosis?
4. The study requires consumer participants to be between the ages of 22-35. Does this describe your age? (Record date of birth)
5. In this study, I plan to ask questions of people who have taken medications for schizophrenia or schizoaffective disorder regarding their experiences. Does this describe your experience? Are you currently taking medication for this condition?
6. This study requires that a family member also participates. This could be any family member who has contact with you at least twice per week. Your family member will also be interviewed and fill out a questionnaire, but all of the meetings will be private. Is there a particular family member who you would agree to have involved with this study? If so, could you provide the telephone number so that I may contact him/her?
7. What is your current living arrangement?
8. Have you ever been hospitalized for your mental illness? If so, when was the last time?
9. Do you receive psychiatric care from a doctor or therapist on a regular basis?
10. Do you have any questions so far about the study?

11. Are you interested in participating?

\* (Explain that if they are not chosen for the study, it is by no fault of their own. Not being selected for the study will be only in the instance that criteria are not met as approved by the Towson University IRB).

**Notes:**

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Family Name: \_\_\_\_\_

Thank you for agreeing to talk with me about this important study. As you may know, your [relative] has expressed interest in participating in this study, and has also identified you as a close family member who may be interested. The main purpose of this telephone conversation is to briefly describe the study and see if you would like to participate. If you are, we will set up a time to meet to begin the study. Please ask any questions that you have as we talk today. Also, I will provide you with my phone number and e-mail address so that you can contact me anytime with questions.

(Explain the main purpose of the study and the methodology, followed by a discussion that includes the following):

1. I would be interested to know more about you, and glad to answer any questions you have for me. Would you mind telling me a little bit about yourself?
2. This study requires that family members have contact with their relative at least twice per week. Does this describe your situation?
3. This study will ask consumers with schizophrenia or schizoaffective disorder and their families about medication adherence and their experiences. Does this describe your experience? Has [your relative] had difficulty, past or present, with deciding to take his/her medications?

\* (Explain: In order to participate in the study, both consumer and family are part of the study. Therefore, if one party chooses not to participate, participants cannot be selected for the study.)

\*\* (Explain: If consumer or families are not selected for this study, it is by no fault of their own. Not being selected for the study will be only in the instance that criteria are not met as approved by the Towson University IRB).

**Notes:**

## Appendix E

**Informed Consent: Consumer**

**Title of study:** Medication Adherence, Social Support, and Recovery:  
Perspectives of Consumers with Schizophrenia and their Families

**Description of Research Project:**

The purpose of this study is to find out more about what it is like to take medications. For example, the researchers would like to know what has been helpful and not helpful when you take medications for your mental illness. We would like to know if there have been times that you decided to stop or change your medications for any reason. We would also like to find out more about others who support you, and how you view recovery from mental illness. The interviewer in this study works with people who are diagnosed with schizophrenia, and would like to learn more about experiences with medications in order to best help people that live with this illness. We will also meet privately with a family member who is close to you so that we can best help families of people with mental illness.

In order to participate in this study you must:

- Be 22-35 years of age
- Diagnosed with schizophrenia or schizoaffective disorder
- Have been mentally ill for 2 years or more
- Be willing to discuss your experiences with medication
- Have one family member agree to participate in this study who has contact with you at least twice per week

**Description of Methodology:**

The researchers will ask you to participate in:

- Demographic Questionnaire: You will be asked to fill out a questionnaire that asks you information about yourself. For example, we would like to know your age, gender, who you live with, who your provider is, and how long you have lived with your mental illness, to name a few.
- Recovery Attitudes Questionnaire (RAQ-21) [Steffen & Wishnick, 1999]: You will be asked to fill out a questionnaire that asks about your beliefs about recovery from mental illness. For example, you will decide whether you strongly agree, agree, are neutral, disagree, or strongly disagree with 21 statements about recovery. There are no right or wrong answers.

- Mental Health Recovery Measure (MHRM) [Young & Bullock, 2003]: You will be asked to answer questions about how you view your own recovery. Again, you will decide whether you strongly agree, agree, are neutral, disagree, or strongly disagree with 30 statements about your recovery. There are no right or wrong answers.
- Two audio-taped interviews/One telephone interview: One interviewer will ask you questions about your medication experiences. The first interview will take about 1 ½ to 2 hours. The second interview will take about 1 – 1 ½ hours. The third interview by telephone will last for approximately ½ hour – 1 hour. In-person interviews will take place at a convenient, public location (such as a room in a public library). The interviewer and participant can decide on the time and place to meet beforehand.

The purpose of the first interview is to first get to know you, what you do in your daily life, and to ask you questions about your medication routine. The purpose of the second interview is to ask you more about times when you may have changed or stopped your medications in some way (known as non-adherence). Also, during the second interview, you will be asked about your views of support and recovery. The purpose of the third interview is to make sure that the interviewer understands what you wanted to say.

The reason the interviews are audio-taped is to help the interviewer remember what you said. Taping the interview is preferred rather than taking written notes because the interviewer can pay more attention to what you are saying.

### **Assurances:**

The information you share in the interview will not be disclosed to your family member who is participating. Likewise, your family member's interviews will not be shared with you since they are designed to be kept private and confidential.

The researchers will listen to the audio-taped interviews and write everything you said and also look at your questionnaires. We will decide how to put the information into categories or themes. Your name will not be used with the exception of the signed informed consent. Code numbers will be used instead of your name. We will make every effort to keep your participation in this study confidential. Also, your family's name will not be used, and will not be able to be identified by other people.

All written information will be kept in a locked file cabinet in the researchers' offices. All information stored on the computer will be password protected and only accessible to the researchers in this study. The interview and questionnaires are confidential, and will not be shared with other people outside of this study. The information may be used to publish in a medical journal, but nobody who reads the article would be able to identify

you or your family. During the interview, if you happen to mention names or places that could identify you, we will not use those names or places when we write. Instead, we will change the names or places to protect your identity or just leave out the information. All of the computer and written information from this study will be destroyed in 3 years. Until then, all information is safe and secure to protect your identity.

Confidentiality may be broken if there is concern for somebody's immediate health or safety. If researchers have reason for immediate safety concern, you agree to allow the researcher to contact your medical provider and/or family member for purposes of your health and safety. If you agree, please provide us with your medical provider's (psychiatrist or therapist) name and contact information below:

Name of medical provider: \_\_\_\_\_

Telephone number: \_\_\_\_\_

Your participation in this study is completely voluntary, of your own will. There may not be direct advantages from participation in this study; however it is possible that you may receive a therapeutic benefit as you verbally share thoughts and feelings. No health risks are expected in this study, but some of the questions may cause discomfort, stress or anxiety. You can choose to skip questions or stop the interview at any time. You are free to change your mind about participating in this study at any time. If you change your mind, nobody will be upset with your decision and there will be no harmful effects on your reputation, involvement, care, or participation in community groups. You are free to ask questions about this study at any time.

In gratitude for your participation in this study, you will receive a total of \$40.00 in gift cards to local retail establishments. One gift card in the amount of \$20.00 will be issued at the completion of the second interview meeting. The final gift card in the amount of \$20.00 will be issued at the completion of the third interview meeting.

Principal Investigator:

Susan Krutis, M.S.Ed., OTR/L

Occupational Therapist

Doctoral student, Towson University

susanot@live.com

443-340-2312

Faculty Sponsor: M. Beth Merryman, Ph.D., OTR/L  
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Towson IRB: Dr. Debi Gartland  
Chair, Institutional Review Board (IRB)  
Towson University (Maryland)  
Office of University Research Services  
Ours@towson.edu  
410-704-2236

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Signature of Participant

Date

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Signature of Witness

Date

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Signature of Principal Investigator

Date

## Appendix F

**Informed Consent: Family**

**Title of study:** Medication Adherence, Social Support, and Recovery:  
Perspectives of Individuals with Schizophrenia and their Families

**Description of Research Project:**

The purpose of this study is to learn about what it is like for people with schizophrenia and schizoaffective disorder to take medications. In addition, we would like to understand your experiences as a family member of a person with mental illness in regards to taking medications. For example, we would like to know more about your experiences, challenges, and roles related to medication management for your family member. We would like to know more about times that your loved one decided to change or stop their medications, and how you experienced this as a family. We would like to understand your beliefs about recovery from mental illness as well. The interviewer works with people who are diagnosed with schizophrenia and their families, and would like to gain knowledge in order to best help those who live with this illness. We will also meet privately with your relative with mental illness as part of this study.

In order to participate in this study you must:

- Be 18 years of age or older
- Be a relative of a young adult who has schizophrenia or schizoaffective disorder who is between the ages of 22-35 and has been mentally ill for at least 2 years
- Have contact with your relative who is mentally ill at least twice per week
- Have a relative who is willing to discuss their experiences with medications

**Description of Methodology:**

The researchers will ask you to participate in:

- Demographic Questionnaire: You will be asked to fill out a questionnaire that asks you information about yourself and your family. For example, we would like to know the nature of your relationship with your loved one, marital status, education level, medication challenges experienced by your loved one and family, and your support system to name a few.
- Recovery Attitudes Questionnaire (RAQ-21) [Steffen & Wishnick, 1999]: You will be asked to fill out a questionnaire that asks about your beliefs about recovery from mental illness. For example, you will decide whether you strongly agree,

agree, are neutral, disagree, or strongly disagree with 21 statements about recovery. There are no right or wrong answers.

- One audio-taped interview/One telephone interview: One interviewer will ask you questions about your family's experiences with a loved one who takes medication for mental illness, and about times your loved one decided to stop or change his or her medications. The interview will take about 2 to 2 ½ hours. The second interview by telephone will last for approximately ½ hour to 1 hour. The in-person interview will take place at a convenient, public location (such as a room in a public library). The interviewer and participant can decide on the time and place to meet beforehand.

The purpose of the first interview is to ask questions about you, your family life, and the family's experiences with a relative who takes medication for mental illness. Also, you will be asked about your perspectives on recovery. The purpose of the second telephone interview is to ask any final questions and to make sure that the interviewer understands what you intended to say.

The reason the interview is audio-taped is to help the interviewer remember what you said. Taping the interview is preferred rather than taking written notes because the interviewer can pay more attention to what you are saying.

### **Assurances:**

The information you share in the interview will not be disclosed to your family member who is participating. Likewise, your family member's interviews will not be shared with you since they are designed to be kept private and confidential.

The researchers will listen to the audio-taped interviews and write everything you said and also look at your questionnaire. We will decide how to put the information into categories or themes. Your name will not be used with the exception of the signed informed consent. We will use code numbers instead of your name and we will make every effort to keep your participation in this study confidential. Also, your relative's name will not be used, and will not be able to be identified by other people.

All written information will be kept in a locked file cabinet in the researchers' offices. All information stored on the computer will be password protected and only accessible to the researchers in this study. The interview and questionnaires are confidential, and will not be shared with other people outside of this study. The information may be used to publish in a medical journal, but nobody who reads the article would be able to identify you or your family member. During the interview, if you happen to mention names or places that could identify you, we will not use those names or places when we write. Instead, we will change the names or places to protect your identity or just leave out the

information. All of the computer and written information from this study will be destroyed in 3 years. Until then, all information is safe and secure to protect your identity.

Confidentiality may be broken if there is concern for somebody's immediate health or safety.

Your participation in this study is completely voluntary, of your own will. There may not be direct advantages from participating in this study; however it is possible that you may receive a therapeutic benefit as you verbally share thoughts and feelings. No health risks are expected in this study, but some of the questions may cause discomfort, stress or anxiety. You can choose to skip questions or stop the interview at any time. You are free to change your mind about participating in this study at any time. If you change your mind, nobody will be upset with your decision and there will be no harmful effects on your reputation, involvement, or participation in community groups. You are free to ask questions about this study at any time.

In gratitude for your participation in this study, you will receive a \$20.00 gift card to a local retail establishment, to be issued at the completion of the second interview meeting.

Principal Investigator:

Susan Krutis, M.S.Ed., OTR/L  
Occupational Therapist  
Doctoral student, Towson University  
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Faculty Sponsor:

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Occupational

Towson IRB:

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Chair, Institutional Review Board (IRB)  
Towson University (Maryland)  
Office of University Research Services  
Ours@towson.edu  
410-704-2236

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Signature of Participant

Date

---

Signature of Witness

Date

---

Signature of Principal Investigator

Date

## Appendix G

### Consumer: Interview #1 Guide

#### Medication Adherence, Social Support, and Recovery: Perspectives of Consumers with Schizophrenia and their Families

Meet in private location of consumer's choice. Initially, will meet one another informally and offer the opportunity to answer questions about the study. If consumer agrees to participate, consent form will be reviewed and signed. Audio-taped interview session one will begin after consent.

The following questions may be suitable for the meeting depending on comfort level, time constraints, and situational context. The order of questions may change, or questions may be skipped altogether as appropriate.

---

#### Getting to Know You

During our phone conversation, I enjoyed learning a little bit about you. Today, I'd like to begin to find out more about you and your life, because it will help me to better understand your experiences with medications. So, let me start by asking you a few questions about you before moving onto the topic of your medications.

1. First, I wonder what a typical day is like for you. (e.g. from the time you arise until bed)
  - a. Are your weekdays different from your weekends?
  - b. Are you working now? If not, have you worked in the past?
  - c. Are there any activities that you find you need help with?
  - d. Do you spend time socializing with other people on a typical day?
2. What sorts of activities do you enjoy doing now?
  - a. How much time do you spend doing things you enjoy?
3. How satisfied are you with your life right now?
  - a. What means the most to you in your life?
  - b. Do you feel you, or others, are in control of your life decisions?
  - c. How confident are you that you can accomplish your goals in life?

### Medications and Illness Management

Now I'd like to switch gears a bit and ask you more about taking medications for your mental illness.

1. Can you please describe your medication routine?
  - a. When do you take your medications?
  - b. What are the names of your current medications?
  - c. How do you remember to take your medications? (Strategies, alarm, other people)
  - d. Have you ever had the experience of forgetting to take your medications?
  - e. Have you ever needed help from other people to take your medications?
2. I am interested to know more about where you usually keep your medications at home.
  - a. Does the location ever change?
  - b. Is there a reason that you keep your medications in this location?
  - c. Is there any particular way you organize your medications? If so, why?
  - d. How do you go about getting your prescriptions refilled? (e.g. when do you arrange for a refill?; do you need help?; how do you pick it up?; any lab work required on a regular basis?)
3. Have your medications helped you? If so, how?
  - a. Are there some medications that have helped more than others?
4. Have your medications ever not helped you? If so, please explain.
  - a. Have your medications been changed over the years since you first were diagnosed? Were the changes helpful or not helpful to you?
5. What was it like for you the first time you took medication for this illness?
  - a. What was your reaction when you first heard that you were being prescribed medication?
  - b. Did your reaction change over time?
6. Since then, have there ever been times that you weren't sure you wanted to take medications? If so, what did you decide to do?
  - a. Did you ever decide to change or stop your medications? Please explain.

I am still interested in knowing more about you and how you feel about your medications. I also would like to know about your family support and ideas about mental health recovery. I would

like to explore this with you during our next two interviews. If you agree, I'd like to schedule the next interview with you. After that interview and filling out two questionnaires, you will receive the first of two gift cards for your participation in this study.

**Notes:**

## Appendix H

### Consumer: Interview #2 Guide

#### Medication Adherence, Social Support, and Recovery: Perspectives of Consumers with Schizophrenia and their Families

Last time we met, I got to know more about you. You also shared some information about your medications. When we left off, you were telling me about times when you (thought about or decided) to (change or stop) your medications. Today, I am interested in understanding more about your experience with this. I'd like to ask you more questions, if that is okay. After the interview, I will also ask you to complete two short questionnaires.

---

1. What is it like for you to take medications for your mental illness?
  - a. How have your feelings about medications changed over time?
  - b. What first comes to mind when you think about taking medications for your mental illness?
2. You have shared that there have been times when you struggled with the decision to keep taking your medication. Please tell me more about the times that you decided to (e.g. change or stop) medications.
  - a. What were the reasons you decided to (e.g. change or stop) medications?
  - b. How long did it take for you to make the decision? What issues were you thinking about to help you make the decision?
  - c. If you (e.g. changed or stopped) your medications, describe the period of time when you were (e.g. taking your medications differently than prescribed or off medications).
  - d. Did you ever decide to return to taking medications the way it was prescribed by your doctor? If so, how did you come to this decision?
  - e. How did other people in your life react to your decision? (If they were aware)
3. Describe the people who support you with your illness. Describe your family members who support you with illness.
  - a. What role does your family play in terms of your medication?
  - b. How do [these individual(s)] help you with your medications?
  - c. How do you express your views about medications to [these individual(s)]?

- d. How do [these individual(s)] respond or react to your views about medications?
4. Describe what has been helpful to you in terms of taking medications regularly.
5. Describe what has hindered you in terms of taking medications regularly.
6. Please tell me about your views on recovery from mental illness. \*If you are not familiar with this term, “*Some people have defined recovery as the process of moving forward with life with a sense of hope and control over their choices, even though symptoms of mental illness may still be present. Many people also feel that they have been helped toward recovery by others who support them.*” What are your thoughts?
- a. Describe your views about medication in your recovery.
- b. How are medications helpful or not helpful in your recovery?

Thank you so much for sharing your experiences with me. I’d like to have you fill out these brief questionnaires about recovery.

(After questionnaires): I’d like to thank you by giving you the first of your gift cards (20.00). I am grateful for your time and that you are helping me to understand what it is like to take medications. If it is okay with you, I will meet with you for a shorter session to ask you a few more questions. After that last interview, I will bring you the second gift card (20.00).

\*(Follow-up questions will be determined through listening to audio-tapes of first two interviews)

## Appendix I

### Family: Interview #1 Guide

#### Medication Adherence, Social Support, and Recovery: Perspectives of Consumers with Schizophrenia and their Families

Meet in private location of family's choice. Initially, will meet one another informally and offer the opportunity to answer questions about the study. If family agrees to participate, consent form will be reviewed and signed. Audio-taped interview session one will begin after consent.

The following questions may be suitable for the meeting depending on comfort level, time constraints, and situational context. The order of questions may change, or questions may be skipped altogether as appropriate.

I enjoyed learning more about you when we talked on the phone. I am interested to know more about you and your family. Today, I'd like to start by asking you a few questions about you and your daily life. Starting with these questions about your daily life will help me to better understand your experiences with medication adherence as a family member.

#### Getting to Know You

1. First, what is a typical day like for you?
  - a. Are you currently working?
  - b. How do you feel about the balance of activities in your daily schedule?
  - c. What hobbies do you enjoy? How much time is spent doing enjoyable activities?
  - d. Are social activities a part of your regular routine?
2. How satisfied are you with your life right now?
  - a. What means the most to you in your life?
3. How would you describe your family relationships?
  - a. Does your family have a preferred way of communicating with one another?
  - b. How does your family resolve conflicts?
  - c. How has the family dealt with the challenges of life with mental illness?

#### Medication Adherence, Social Support, and Recovery

4. Please tell me about your experiences with psychiatric medications for your [relative]?

a. Do you play a role in terms of helping [your relative] with taking medications? If so, how?

5. Please describe periods of time when your [relative] has struggled with the decision of whether or not to take medications.

a. What was your impression of [your relative's] reasons for (e.g. considering, altering, stopping) his/her medications?

b. Can you recall an example of a time when [your relative] made a decision to (e.g. change, stop) his/her medications?

c. How did his or her health care team respond? (If they were aware)

6. How has your family been affected when your relative does not take medications as prescribed?

a. How are views about medications expressed by your [relative]?

b. Describe how your family responds to your [relative's] views about medications.

c. What supports have you relied on as a family?

7. What has worked well for helping your [relative] take prescribed medications regularly?

8. What has hindered your [relative] in taking prescribed medications regularly?

9. Describe what has been most challenging for you and your family in terms of medication adherence for your [relative]?

10. Please tell me about your views on recovery from mental illness. *\*If you are not familiar with this term, "Some people have defined recovery as the process of moving forward with life with a sense of hope and control over their choices, even though symptoms of mental illness may still be present. Many people also feel that they have been helped toward recovery by others who support them."* What are your thoughts?

a. How do you believe your [relative] views the role of medications in his/her recovery?

b. How do you view the role of medications in his/her recovery?

c. How do other close family members view the role of medications in his/her recovery?

Thank you for sharing all of this valuable information with me. This is certainly going to help me understand family experiences so much more. I have one questionnaire about recovery that I would like you to complete before we end today.

If you agree, I'd like to schedule the next interview with you. This last interview is likely to be much shorter than this one. I will ask you a few more questions for clarification, to be sure that I

understand what you have said in this interview. During our next meeting, I will also bring you a small token of my appreciation (20.00 gift card) for your participation in this study.

\*(Follow-up questions will be determined through listening to audio-taped interview)

**Notes:**

## Appendix J

**Demographic Questionnaire: Consumer**

Please complete the following questions about yourself, so that I will be able to understand a little more about you (**Circle corresponding letter and/or write-in response**):

- A. Your gender: \_\_\_\_\_
- B. Your race: \_\_\_\_\_
- C. Your date of birth (Month/Day/Year): \_\_\_\_\_
- D. Your highest level of education completed: \_\_\_\_\_
- E. Your current marital status: \_\_\_\_\_
- F. Which of the following best describes your living situation?
1. Living alone
  2. Living with roommate(s)
  3. Living with family
  4. Living with assistance from a caregivers/medical providers
  5. Living in an institutional environment (hospital)
  6. Other (Please explain): \_\_\_\_\_
- G. Which of the following best describes your financial support? (Circle all that apply):
1. Full-time employment (40 hours per week)
  2. Part-time employment (20 hours per week)
  3. Family
  4. Personal savings account
  5. Social security income or social security disability income (SSI/SSDI)
  6. Occasional employment (temporary or short-term jobs)
  7. None of the above
  8. Other: \_\_\_\_\_
- H. What is your current income in dollars?
1. Under \$25,000
  2. \$25,000- \$30,000
  3. \$31,000- \$60,000
  4. \$61,000- \$100,000
  5. Over \$100,000
  6. Would rather not say

I. How long have you been receiving medical treatment for your psychiatric illness?

1. Less than 1 year
2. 2-3 years
3. 4-5 years
4. 6-10 years
5. 11-15 years
6. 16-20 years
7. 20+ years
8. I am not sure

J. About how often do you utilize medical treatment for your psychiatric illness?

1. Daily
2. Weekly
3. Bi-weekly
4. Monthly
5. Quarterly
6. Semi-annually (every 6 months)
7. Annually
8. Not applicable
9. Other: \_\_\_\_\_

K. Are you currently taking medication for a psychiatric illness?

1. Yes
2. No
3. I am not sure

L. Have you ever decided to stop taking your medications?

1. Yes
2. No
3. I am not sure
4. Not applicable

M. Have you ever decided to change your medications, such as dosage or scheduled times?

1. Yes
2. No
3. I am not sure
4. Not applicable



## Appendix K

**Demographic Questionnaire: Family**

Please complete the following questions about yourself, so that I will be able to understand a little more about you (**Circle corresponding letter and/or write-in response**):

A. Your gender: \_\_\_\_\_

B. Your race: \_\_\_\_\_

C. Your date of birth (Month/Day/Year): \_\_\_\_\_

D. Your highest level of education completed: \_\_\_\_\_

E. Your current marital status: \_\_\_\_\_

F. Which of the following best describes your relationship with your relative with mental illness?

1. Parent
2. Grandparent
3. Sibling
4. Spouse
5. Non-immediate family (e.g. aunt, uncle, cousin)
6. Other: \_\_\_\_\_

G. What is your current household income in dollars?

1. Under \$25,000
2. \$25,000- \$30,000
3. \$31,000- \$60,000
4. \$61,000- \$100,000
5. Over \$100,000
6. Would rather not say

H. How many children do you have? \_\_\_\_\_

I. Which family members reside in your home? (Circle all that apply):

1. Spouse
2. Adult children
3. Teenage children
4. Elementary aged children
5. Infants/Toddlers
6. Elderly relatives
7. Just myself
8. Other: \_\_\_\_\_

J. How long ago did your loved one begin utilizing medical treatment for psychiatric illness?

1. Less than 1 year ago
2. 2-3 years ago
3. 4-5 years ago
4. 6-10 years ago
5. 11-15 years ago
6. 16-20 years ago
7. 20+ years ago

K. How often has your loved one struggled with the decision to take medication for psychiatric illness?

1. Very Frequently
2. Frequently
3. Occasionally
4. Rarely
5. Very Rarely
6. Never

L. How often has your relative stopped (or altered) prescribed medication for psychiatric illness?  
(Place an "X" along this line to indicate how often):

| \_\_\_\_\_ | \_\_\_\_\_ | \_\_\_\_\_ | \_\_\_\_\_ |

Never  
frequently

Rarely

Occasionally

Frequently

Very

M. What reasons has your relative cited for stopping (or altering) medication? (Circle all that apply):

1. Side effects (e.g. fatigue, weight gain)
2. Not benefitting symptoms
3. Poor alliance with medical providers (e.g. psychiatrists, therapists)
4. Feels better after taking medication and no longer feels he/she needs it
5. Believes that he or she does not have an illness that requires medication
6. Fear or distrust related to delusional thinking
7. Fear or distrust not related to delusional thinking
8. Complicated schedule
9. Forgetful
10. Stigma
11. Not feeling like him or herself on medication
12. Other: \_\_\_\_\_

N. How many days in a normal week do you have face to face contact with your relative who is mentally ill?

1. None
2. 1-2 times per week
3. 3-4 times per week
4. 5-7 times per week
5. Other (Please explain): \_\_\_\_\_

O. Which of the following best describes your family support system? (Circle all that apply):

1. Talking to family and friends who understand
2. Participating in web-based blogs or support groups for families of those with mental illness
3. Support or educational groups in the community (e.g. NAMI)
4. Advocacy-related activities to promote awareness of mental illness
5. Other: \_\_\_\_\_
6. Do not feel our family has support at this time

## Appendix L

**Mental Health Recovery Measure (MHRM)®**

(Young &amp; Bullock, 2003)

Name: \_\_\_\_\_ Date: \_\_\_\_\_

The goal of this questionnaire is to find out how you view your own current recovery process. The mental health recovery process is complex and is different for each individual. There are no right or wrong answers. Please read each statement carefully, with regard to your own current recovery process, and indicate how much you agree or disagree with each item by filling in the appropriate circle.

SD = *Strongly Disagree* D = *Disagree* NS = *Not Sure* A = *Agree* SA = *Strongly Agree*

- |   | SD                    | D                     | NS                    | A                     | SA                    |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1. I work hard towards my mental health recovery.                               | <input type="radio"/> |
| 2. Even though there are hard days, things are improving for me.                | <input type="radio"/> |
| 3. I ask for help when I am not feeling well.                                   | <input type="radio"/> |
| <hr/>   |                       |                       |                       |                       |                       |
| 4. I take risks to move forward with my recovery.                               | <input type="radio"/> |
| 5. I believe in myself.   | <input type="radio"/> |
| 6. I have control over my mental health problems.                               | <input type="radio"/> |
| <hr/>   |                       |                       |                       |                       |                       |
| 7. I am in control of my life.  | <input type="radio"/> |
| 8. I socialize and make friends.  | <input type="radio"/> |
| 9. Every day is a new opportunity for learning.                                 | <input type="radio"/> |
| <hr/>   |                       |                       |                       |                       |                       |
| 10. I still grow and change in positive ways despite my mental health problems. | <input type="radio"/> |
| 11. Even though I may still have problems, I value myself as a person of worth. | <input type="radio"/> |
| 12. I understand myself and have a good sense of who I am.                      | <input type="radio"/> |
| <hr/>   |                       |                       |                       |                       |                       |
| 13. I eat nutritious meals everyday.  | <input type="radio"/> |
| 14. I go out and participate in enjoyable activities every week.                | <input type="radio"/> |
| 15. I make the effort to get to know other people.                              | <input type="radio"/> |

Please continue on next page.

SD = *Strongly Disagree* D = *Disagree* NS = *Not Sure* A = *Agree* SA = *Strongly Agree*

	SD	D	NS	A	SA
16. I am comfortable with my use of prescribed medications.	<input type="radio"/>				
17. I feel good about myself.	<input type="radio"/>				
18. The way I think about things helps me to achieve my goals.	<input type="radio"/>				
<hr/>					
19. My life is pretty normal.	<input type="radio"/>				
20. I feel at peace with myself.	<input type="radio"/>				
21. I maintain a positive attitude for weeks at a time.	<input type="radio"/>				
<hr/>					
22. My quality of life will get better in the future.	<input type="radio"/>				
23. Every day that I get up, I do something productive.	<input type="radio"/>				
24. I am making progress towards my goals.	<input type="radio"/>				
<hr/>					
25. When I am feeling low, my religious faith or spirituality helps me feel better.	<input type="radio"/>				
26. My religious faith or spirituality supports my recovery.	<input type="radio"/>				
27. I advocate for the rights of myself and others with mental health problems.	<input type="radio"/>				
<hr/>					
28. I engage in work or other activities that enrich myself and the world around me.	<input type="radio"/>				
29. I cope effectively with stigma associated with having a mental health problem.	<input type="radio"/>				
30. I have enough money to spend on extra things or activities that enrich my life.	<input type="radio"/>				

*Thank you for completing this measure.*

The MHRM<sup>®</sup> was developed with the help of mental health consumers by researchers at the University of Toledo, Department of Psychology. This research was supported through a grant from the Ohio Department of Mental Health, Office of Program Evaluation and Research. For further information, please contact Wesley A. Bullock, Ph.D. at (419) 530-2721 or email: [wesley.bullock@utoledo.edu](mailto:wesley.bullock@utoledo.edu).

## Appendix M

## Recovery Attitudes Questionnaire (RAQ-21)

Date \_\_\_\_/\_\_\_\_/\_\_\_\_

ZIP Code \_\_\_\_-\_\_\_\_-\_\_\_\_

**RECOVERY**

Recovery is a process and experience that we all share. People face the challenge of recovery when they experience the crises of life, such as the death of a loved one, divorce, physical disabilities, and serious mental illnesses. Successful recovery does not change the fact that the experience has occurred, that the effects are still present, and that one's life has changed forever. Rather, successful recovery means that the person has changed, and that the meaning of these events to the person has also changed. They are no longer the primary focus of the person's life (Anthony, 1993).

We are interested in measuring your beliefs about the concept of recovery from mental illnesses. Please read each of the following statements and using the scale below mark the rating that most closely matches your opinion.

	<b>SA</b> Strongly Agree	<b>A</b> Agree	<b>N</b> Neutral	<b>D</b> Disagree	<b>SD</b> Strongly Disagree					
1.						SA	A	N	D	SD
2.										
3.						SA	A	N	D	SD
4.						SA	A	N	D	SD
5.						SA	A	N	D	SD
6.						SA	A	N	D	SD
7.						SA	A	N	D	SD
8.						SA	A	N	D	SD
9.						SA	A	N	D	SD
10.						SA	A	N	D	SD
11.						SA	A	N	D	SD
12.						SA	A	N	D	SD
13.						SA	A	N	D	SD
14.						SA	A	N	D	SD
15.						SA	A	N	D	SD
16.						SA	A	N	D	SD

- 17. Recovery can lessen the symptoms of mental illness..... SA A N D SD
- 18. Recovering from the consequences of mental illness is sometimes more difficult than recovering from the illness itself. SA A N D SD
- 19. People who are recovering from mental illness can help others to recover..... SA A N D SD
- 20. The family may need to recover from the impact of a loved one's mental illness..... SA A N D SD
- 21. To recover requires courage..... SA A N D SD

**BACKGROUND INFORMATION:** The questionnaire is anonymous; please do not sign your name. The next few questions are for demographic information only. Please check the most appropriate response.

**How would you describe yourself?**  
(Check all that apply)

- Mental Health Consumer/client
- Mental Health Professional
- Family member of a loved one with mental illness
- Student
- Other (specify) \_\_\_\_\_

**Do you consider yourself to have a mental illness?**

- Yes For how long? \_\_\_\_\_
- No

**Do you consider yourself to be recovering?**

- Yes For how long? \_\_\_\_\_
- Sometimes
- No

**If you are a professional, please indicate your discipline:**  
(Check all that apply)

- Case Manager
- Social Worker
- Psychologist
- Psychiatrist
- Nurse
- Support Staff
- Paraprofessional
- Academician
- Therapist
- Administrator/Planner
- Other (specify) \_\_\_\_\_

**How many years have you worked with people with mental illness?**

\_\_\_\_\_

**What is your age?**

- 20 or less
- 21-30
- 31-40
- 41-50
- 51-60
- 61 or over

**What is your ethnic/racial background?**

- Asian American/Pacific Islander
- African American
- Appalachian
- Hispanic
- Native American
- White, Non-Hispanic
- Other (specify) \_\_\_\_\_

**What is your gender?**

- Male
- Female

**Thank you for taking the time to fill out the questionnaire.**

Please direct any comments or questions to:  
John Steffen at (808) 935-8397; sjohn@hawaii.edu  
Hamilton County Recovery Initiative Research Team (HCR-RT)

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Supported by the Office of Program evaluation & Research, Ohio Department of Mental Health  
Sponsored by the Mulltidisciplinary Program Consortium, A Center for Training and Research In Serious Mental Illness  
HCRI-RT, 1997

## Appendix N

## Codebook

Self	Environment/Context	Performance	Outcome/ Lifestyle Choices	Change Process
<b>(SC)</b> Self Concept (Who am I?)	<b>(EFm)</b> social; Family			<b>(CD)</b> Discover need for change; area for change
<b>(SE)</b> Self Efficacy (Am I worthwhile? Can I do it?)	<b>(EFr)</b> social; Friends	<b>(PSE)</b> Self- Expression		<b>(CG)</b> Goal identification
<b>(SL)</b> Life Perspective (views, beliefs, philosophy, values about living)	<b>(EMh)</b> social; Mental health Community Non-medical; consumer/family driven	<b>(PLB)</b> Life Behavior	<b>(OD)</b> Do life activity/not do life activity	<b>(CTE)</b> Trial and error
<b>(SM)</b> Medication Perspective (views, beliefs, philosophy, values about medications)	<b>(EHC)</b> social; Health Care System		<b>(OA)</b> Adherence to medication/Non- adherence to medication	<b>(CMD)</b> Make decision
<b>(SH)</b> Health Perspective (views, beliefs, philosophy, values about health)	<b>(ES)</b> social; Society	<b>(PHB)</b> Health behavior	<b>(OC)</b> Implement adaptation	

<p><b>(Sch)</b> Change Perspective (views, beliefs, philosophy, values about change)</p>	<p><b>(EE)</b> Economic</p>	<p><b>(OI)</b> Integration Living out choices; obvious in routine</p>	<p><b>(CW)</b> Change ways: explore ways to implement goal; consider adaptations</p>
<p><b>(SF)</b> Future Perspective (Hope versus despair; views, beliefs, philosophy, values about future)</p>	<p><b>(EPH)</b> physical; Home</p>		
<p><b>(SS)</b> Support Perspective (views, beliefs, philosophy, values about support)</p>	<p><b>(EPC)</b> physical; community; outside home</p>		
<p><b>(SI)</b> Illness Experience (effects of illness on self)</p>	<p><b>(EM)</b> properties of medication</p>		

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- Krutis, S.D., Robertson, S.C., & Paul, S.M (*in progress*). Occupational therapy and medication adherence: A pilot study examining clients' experiences with psychotropic medications for schizophrenia and schizoaffective disorder.
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## Curriculum Vitae

**Susan D. Krutis, M.S.Ed., OTR/L****PERSONAL DATA**

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**EDUCATION**

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**Sc.D.**

Towson University - Towson, MD

Occupational Science

August 2012

**M.S.Ed.**

Johns Hopkins University - Baltimore, MD

Concentration: Adult Learning & Higher Education

May 2001

**B.S.**

Virginia Commonwealth University

Medical College of Virginia - Richmond, VA

Occupational Therapy

December 1995

## **CLINICAL EXPERIENCE**

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### **National Institutes of Health**

Bethesda, MD

May 2003- Present

Senior occupational therapist, half-time, independent contractor

National Institute of Mental Health (NIMH), Clinical Brain Disorders Branch

Inpatient Schizophrenia Research Program, NIMH

- Design clinical occupational therapy programs for patients with schizophrenia and other severe mental illnesses
- Conduct clinical evaluation and intervention utilizing group, individual, and community-based programming
- Apply the Assessment of Motor and Process Skills as a clinical evaluation tool in planning for intervention and discharge needs
- Identify individual needs for productive engagement in occupation and supervised patients in volunteer work settings following research participation
- Developed unit-based interdisciplinary committee to strengthen therapeutic relationships and promote beneficial milieu for patients
- Presented staff development modules to integrate novel patient programs into interdisciplinary clinical practices
- Refine and improve role of occupational therapy in clinical research setting based on literature reviews, interdisciplinary collaboration, and expertise in functional assessment
- Completed qualitative study examining clients' experiences with medications
- Completed mixed methods study examining consumer and family perspectives of medication experiences and recovery in mental illness
- Collaborated with colleagues to produce and edit manuscript for submission to scholarly journal based on results from medication adherence pilot study

- Independently produced theoretical manuscript for submission to scholarly journal analyzing medication adherence through occupational and non-occupational based conceptual models

### **Select Medical Corporation**

Sykesville, MD

November 2002- April 2003

Occupational therapist, per-diem

- Provided comprehensive clinical evaluation and treatment for patients in skilled nursing, assisted living, and long-term care settings
- Designed viable occupational therapy program initiatives consistent with patient needs
- Independently obtained certification in Assessment of Motor and Process Skills and demonstrated the instrument's applicability to the elderly population
- Designed and provided staff and caregiver training to benefit patients diagnosed with various types of dementia

### **Maryland General Hospital, Bryn Mawr Rehabilitation Center**

Baltimore, MD

January 1996- August 2001, full-time staff occupational therapist

August 2001- November 2002, per-diem occupational therapist

- Provided evaluation and intervention for patients on acute care, intensive care, outpatient, transitional care, comprehensive inpatient rehabilitation, and brain injury rehabilitation units
- Specialized in evaluation and intervention of patients with amputation, joint replacement, stroke, and brain injury
- Utilized neurodevelopmental treatment and cognitive-perceptual techniques
- Coordinated student fieldwork program
- Integrated principles and practices of mentorship with new staff members and students
- Designed and developed emerging occupational therapy program for new transitional care unit

## **PUBLICATIONS**

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**Krutis, S.** (2002, December 16). Consider doctoral education. *OT Practice*, 19-22, Bethesda, MD: American Occupational Therapy Association.

*In Progress (editing for submission):*

**Krutis, S., Robertson, S.C., & Paul, S.M. (in progress).** Part I: Occupational therapy and medication adherence: Examining client perspectives on experiences with medications for schizophrenia.

**Krutis, S. (in progress).** Part II: Occupational therapy and medication adherence: Conceptual analysis of medication adherence according to Person-Environment-Occupation and recovery models.

## SCHOLARSHIP

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### Invited Presentations

**Krutis, S.** Consumer and family perspectives of medication experiences for schizophrenia: Case study analysis, Rehabilitation Medicine Grand Rounds, 1.5 hour presentation, National Institutes of Health, Bethesda, MD, 1/15/10.

**Krutis, S., & Robertson, S.C.** Occupational therapy in mental health: Promoting health and participation through engagement in occupation, 2-hour guest lecture, Neuropsychiatry Nurse Fellowship Program, National Institute of Mental Health, Bethesda, MD, 5/22/09.

**Krutis, S.** Design and implementation of an interdisciplinary, recovery-based medication program: Empowering patients with schizophrenia to manage their own health, Rehabilitation Grand Rounds, 1.5-hour presentation, National Institutes of Health, Bethesda, MD, 9/30/06.

Klein, R., **KrutiS, S.**, Merryman, M.B., & Robertson, S.C. Weapons of mass empowerment: Transformative learning and occupational therapy, Maryland Occupational Therapy Association, Annual Conference, 4-hour institute, Catonsville, MD, 11/5/04.

**KrutiS, S.**, & Tasoulis, S. Hemorrhagic cerebrovascular accident: A case study, 3-hour guest lecture, Shenandoah University, Shenandoah, VA, 10/02.

**KrutiS, S.** Bringing occupation back into your practice, Maryland General Hospital, 1-hour presentation, Baltimore, MD, 3/02.

**KrutiS, S.**, & Tasoulis, S. Brain injury: The race toward recovery, Invited 3-hour guest lectures:

Towson University, Towson, MD, 2/02, 10/01, 2/01, 10/00, 2/99

Community College of Baltimore, Catonsville, MD, 10/98

**KrutiS, S.** Multiple Intelligences, Invited 2-hour guest lecture, Towson University, Towson, MD, 11/01.

**KrutiS, S.** Occupational therapy as a career choice, Career day, 30 minute presentation and learning experiences, Baltimore City Public Schools, Baltimore, MD, 1/99, 1/00.

## **In-service Presentations**

**KrutiS, S.**, & Pettit, W. The self-management program: Empowering patients with schizophrenia to direct their lives, 30 minute presentation, National Institute of Mental Health, Bethesda, MD, 6/06.

**KrutiS, S.** Independent medication program: Improving function and compliance, series of 1-hour training presentations, National Institute of Mental Health, Bethesda, MD, 5/06.

**KrutiS, S.** Occupational therapy and placebo research, 30 minute presentation, National Institute of Mental Health, Bethesda, MD, 9/04.

**Krutis, S.** Occupational therapy program proposal: Inpatient schizophrenia research unit, 1-hour presentation, National Institute of Mental Health, Bethesda, MD, 9/03.

**Krutis, S.** The Affolter concept, 2-hour presentation, Maryland General Hospital, Baltimore, MD, 6/98.

## **PROFESSIONAL & COMMUNITY SERVICE**

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Vice President, local Carroll County chapter NAMI, 2006-2007

Editor, NAMI Carroll County Newsletter, 2006-2007

Local chapter representative, 2006 NAMI Annual Conference, appointed by Carroll County chapter, 6/06.

Fundraiser for a special team of walkers, NAMI Walks Campaign, National Institute of Mental Health: 3/06, 3/07, 3/09.

Initiated development of support group services for mothers of colicky babies with local pediatricians, obstetricians, & lactation consultants, 10/05.

Research Assistant, *Brains Rule*, Neuroscience Exposition led by Creighton University, Maryland Science Center, Baltimore, MD, 3/02.

Student Representative, 1994 AOTA Annual Conference, Boston, MA.

## **RESEARCH INTERESTS**

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Medication adherence as occupation according to perspectives of individuals living with schizophrenia or schizoaffective disorder

Recovery in severe and persistent mental illness

Caregiver experiences including quality of life and views of recovery for family members living with chronic mental health conditions.

## TEACHING EXPERIENCE

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### **Towson University, Part-time faculty**

Department of Occupational Therapy & Occupational Science

Towson, MD, January 2001- May 2002

OCTH 221: Clinical Kinesiology: Taught muscle physiology, joint structure, muscle function, analysis of movement, and palpation with focus on application to occupational therapy evaluation and treatment. Prepared lecture and lab instruction and designed examinations, including written and practical portions. Responsible for arranging site visits for practical experience as well as occasional guest speakers in the field. Arranged for additional laboratory experiences as needed to enhance comprehension of material.

Spring 2001: Lecture/Lab

Fall 2001: Lab section

Spring 2002: Lecture/Lab

### **Towson University, Teaching Internship**

Department of Occupational Therapy & Occupational Science

Towson, MD, June 2000- August 2000

OCTH 218: Analysis of Occupational Performance II: Assisted with teaching course in therapeutic media, technology application, job analysis, and health maintenance. Instructed students in lecture and lab material. Gained experience with designing written examinations and understanding grading procedures.

## AWARDS & HONORS

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Graduate Fellowship Award, Towson University, 2009-2010

Graduate Fellowship Award, Towson University, 2001-2002

Summa Cum Laude Graduate Honors, Medical College of Virginia, December 1995 and Johns Hopkins University, May 2001

Pi Theta Epsilon Honor Society, Medical College of Virginia, 1994-1995

President, Student Occupational Therapy Association, Medical College of Virginia, 1994-1995

Adolph D. Williams Scholarship Award for outstanding academic achievement, Medical College of Virginia, 1994-1995

## **CREDENTIALS**

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Licensed, Board of Occupational Therapy Practice, Maryland

Certified, National Board of Certification in Occupational Therapy

Calibrated rater: Assessment of Motor & Process Skills

## **PROFESSIONAL MEMBERSHIPS**

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National Alliance on Mental Illness (NAMI), Loudoun County Chapter, Northern Virginia

