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Walking Alongside Psychosis

**-Strategies of engagement while living with a person with
a serious mental illness**

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Abstract

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Schizophrenia and bipolar disorder are lifelong illnesses that include psychosis and difficulty maintaining stability. These illnesses are also characterized by limited abilities to self-assess and seek treatment when necessary. Informal caregivers of people living with a serious mental illness are often relatives or spouses. The objective of this study was to determine what strategies were used by informal caregivers. Informal caregivers often find themselves in a position of caring for a family member. In order to manage relationships, informal caregivers have developed inventive strategies and roles to cope with long-term care. The study was conducted by means of qualitative interviews with informal caregivers. Use of role-set theory and resilience theory was applied to the data for analysis. Results of this study determined that informal caregivers employ four strategies for maintaining a relationship with the family member; upholding traditional roles, recalibrating expectations, playing along, and separating the illness from the person. Results also concluded that informal caregivers take on three roles in relation to mental healthcare systems. These roles are referred to as becoming the expert, the identity guardian, and the role of ally. Lastly, this study has determined that these informal caregivers exhibit signs of a progression towards resilience whereas caregivers of other forms of long-term illnesses usually experience greater feelings of burnout.

Key words: Caregiver, mental illness, resilience, schizophrenia, bipolar disorder

Preface

I would like to take this opportunity to thank all the people that helped me through this process. To my two daughters, Lucy and Sylvie, thank you for constantly interrupting my writing and being adorable. To my fiancée Frederic, thank you for distracting Lucy and Sylvie long enough for me to finish writing. To my supervisor, Tove Harnett, thank you for your positivity and encouragement, even over video chat. Lastly, I would like to thank all the people that have lived with, experienced, walked alongside, and enjoyed the ups and downs that is living with a person with mental illness. Your stories of love, dedication, and frustration have inspired me.

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1. Introduction

If he mentions religion or anything like that, I am just on, you know. And he's like mom, you know every time I say anything, you're gonna think I'm getting sick again. And I told him, I'm really trying to cool it, but I do have to be on watch because this is a tricky freakin' disorder. I've lived it, I know how it can inch in and all of a sudden the meds don't work. Or you know you're having delusions and you're not talking to me. So the only way I'll be able to relieve that is, how we manage his thing is we have check-ins. We sit down, just together.

-Jackie

Schizophrenia and bipolar disorder are lifelong neuropsychological disorders that limit a person's ability to differentiate delusions from reality (Weimand, 2012). Schizophrenia and bipolar disorder often go hand in hand with other challenges such as drug abuse, multiple diagnoses, and homelessness (Lindqvist, Markström & Roseberg, 2010). Compulsory inpatient treatment is considered a last resort (Emerson, 1976) due to the harmful effects this can have on the patient's personal integrity. Treatment plans are therefore complex and require motivational work by professionals and doctors. An often overlooked aspect of care in these cases is the role of relatives and their motivational strategies in order to get their family members to seek care. Relatives in a caretaking role usually have the most day to day contact with people diagnosed with a serious mental illness and yet they lack a formal role in relation to care provided by mental healthcare systems.

Schizophrenia and bipolar disorder share a common symptom of paranoia which can complicate the process of accepting a diagnosis and receiving treatment. Relatives often play a crucial role in encouraging family members to receive treatment by intervening on their behalf. Relatives of people diagnosed with a serious mental illness experience a double weight of caring for a family member with a lifelong diagnosis as well as the societal stigma that surrounds these diagnoses, which in part leads to psychological distress (Nitsche, Koch & Kallert, 2010). There has been extensive research on the emotional toll taken on relatives in a position to care for the elderly (Almberg, Graftström & Winblad, 1997), for cancer patients (Papastavrou, Charalambous & Tsangari, 2012), and for other diagnoses that require long term care (Degiuli, 2016). While there are similarities in the roll of caretaking across all of these

categories, relatives of those diagnosed with schizophrenia and bipolar disorder are afflicted with the isolating effects of stigma whereas relatives caring for the elderly are more likely to be received with understanding and support (Muralidharan et al., 2016). Relatives of people diagnosed with schizophrenia or bipolar disorder experience the brunt of many of the challenges in encouraging their family members to receive, maintain, and manage treatment. Difficulties surrounding interventions involving family members with paranoia often lead to a delicate balance between maintaining trust in the relationship and weighing concerns of self-harm or harm to others. There is a fine line between respecting the integrity of the family member by encouraging him or her to seek help by whatever means necessary and trusting the family member to make the right choices on his or her own. legally, relatives find themselves in a powerless position without any authority to motivate their family members to seek help.

Many have therefore become adept at developing motivational strategies in critical points of intervention. While research in this area is often focused on the negative aspects of the role of relatives of a person with a serious mental illness, there is little research on the positive outcomes that occur such as motivational strategies and resilience in the face of long-term adversity. These experiences of relatives and their strategies of intervention with a family member living with schizophrenia or bipolar disorder would be able to contribute value to social work and mental health professions.

Understanding vulnerability is a large part of what social workers do. Assessment work is often a critical look at a client's vulnerabilities on a larger scale. This assessment should not only include a client's circumstances, but also the capabilities of the client and his or her ability to cope with negative outcomes (Van Breda, 2018). It is therefore beneficial to be able to look critically at vulnerability without falling into the common misconception that vulnerability is a sign of helplessness. Vulnerability amongst clients may also lead to resilience.

2. Objective

The objective of this study is to explore the experiences of relatives of persons living with a serious mental illness. Particular attention is paid to their challenges regarding interventions on behalf of their family members as well as the strategies developed to motivate their family members to receive care. In order to gain insight into this complicated role, I will seek to answer three research questions:

- 1) What strategies do informal caregivers use to manage a family member's serious mental illness?
- 2) What types of roles do informal caregivers demonstrate in the face of formal support systems?
- 3) How can the role of informal caregiver be understood through resilience theory?

These three questions attempt to address the opposing directions of expectation placed on informal caregivers of people with a serious mental illness. The first question is directed towards the dynamic between informal caregivers and their family members. The second question aims to examine the roles in which informal caregivers place upon themselves while dealing with mental healthcare systems. Lastly, this study attempts to answer how resilience and the role of informal caregiver correspond with each other. This study is designed to answer these questions qualitatively and with the fullest respect towards the integrity of the participants.

3. Background

In order to grasp the difficulties of the role of an informal caregiver to a person with a serious mental illness, it is useful to have an understanding of the challenges schizophrenia and bipolar disorder necessitate. The following section provides a brief description of schizophrenia and bipolar disorder. This section also provides a history of treatment methods. This is necessary because treatment of mental illness from a historical aspect has created a substantial amount of mistrust between informal caregivers and medical professionals. The following section is a description of how a psychotic state may present itself. Finally, a definition of the role of caregiver is provided in order to clarify the definition used in this study.

3.1 Schizophrenia and Bipolar Disorder

Schizophrenia and bipolar disorder are often referred to as more serious mental health conditions compared to other diagnoses such as anxiety disorders or depression (Lindqvist, 2012). Relatives often experience the delusions of family members with a serious mental illness as a challenge to encouraging them to seek professional help. A study that measured the insight levels of people diagnosed with paranoid schizophrenia and their ability to self-assess their own need of care concluded that people with schizophrenia are particularly prone to under-evaluating their need for medical or professional help and they are more resistant to help than others with other forms of mental illness (Papsuev et al., 2017). A Swedish study (Hjärthag, Helldin & Norlander, 2008) aimed to measure the level of burden that relatives of schizophrenics undertake by using the psychometric scale of Care of Burden for Relatives. A compelling result of this study found that relatives of people living with schizophrenia who were not in remission experienced significantly greater family burden (Hjärthag, Helldin & Norlander, 2008). These results indicate that families caring for people living with untreated schizophrenia undergo greater stress.

Relatives lacking legal options for their family members (except in extreme cases of a danger to oneself or others) often resort to unconventional and clever tactics to motivate their family members to receive care. A British study (Scazufca & Kuipers, 1999) identified two methods

relatives implemented while dealing with schizophrenic family members; an avoidance method, or a problem-focused method. I suggest that there are more than two methods and the motivations behind the methods vary.

3.2 Treatment methods

Treatment methods of mental illness have a long history of ineffective and spurious design. Family members of people living with a mental illness have a well-founded right to be skeptical of treatment methods (Kurtz, 2015). While a definition of what is now known as schizophrenia is considered an acceptable diagnosis that requires medical treatment, an historical understanding of the diagnosis has been difficult to pinpoint based on today's model of the DSM-5 (ibid.). Mental illness as a concept did not fully come to the attention of the medical world until the establishment of the study of psychology in the 18th Century (ibid.). Before this, people afflicted by what we now know as mental illness were largely considered a concern solely of the family (ibid.). Family caregivers have been responsible for the majority of people living with a mental illness up until the 19th Century.

Antipsychotic medication was first available in the 1950's with very little understanding of how it affected the brain (Cullberg, Skott & Strålin, 2020). Researchers now know that antipsychotic medication works by blocking the dopamine receptors in the brain, which allows a person experiencing a psychotic state to filter sensations and experiences more effectively and accurately (ibid.). Before medication, the most common form of treatment was isolation in the form of a mental institution where a person diagnosed with a serious mental illness would often worsen due to the negative effects that isolation has on mental health (ibid.). Other common forms of treatment before the 1950's included bloodletting, inducement of fever, castration/ovariectomy, and lobotomies (Kurtz, 2015). Other notable forms of treatment included gardening, manual labor, and even expensive champagne (Kurtz, 2015) which indicates that methods varied so greatly because there was very little understanding of the underlying causes of illness.

3.3 Psychosis: a state of uncertainty

For this study, it is important to understand the underlying factors that contribute to the difficulty of care related to people diagnosed with a serious mental illness involving psychosis. There are different states of psychosis and causes of underlying origins. A person experiencing a psychosis enters different phases. The early phase is characterized by prodromal symptoms (Cullberg, Skott & Strålin, 2020). These symptoms include a withdrawal from social life, difficulty carrying out basic tasks, and a distancing from friends and family. Dissociation is also associated with schizophrenia and bipolar disorder. Dissociation involves what patients have described as a sense of anomaly (Černis, Freeman & Ehlers, 2020). Dissociation can include feelings of detachment to reality, changes in perception, a lack of sensation, and even a sense of heaviness (Černis, Freeman & Ehlers, 2020). The next phase, also known as the first critical period, can involve delusions, auditory hallucinations, and shifts in personality (Cullberg, Skott & Strålin et al., 2020). In this phase, a person may experience symptoms of paranoia, mistrust, increased anxiety, and a difficulty differentiating between his or her reality and the reality that others are experiencing (ibid.).

The final phase, also known as the second critical phase, is when the person begins to recover from the psychosis. The person experiencing a psychosis may now be able to differentiate between the hallucinations or delusions and the world around him or her (Cullberg, Skott & Strålin, 2020). This is often due to hospitalization and medication administered during the first critical phase. A notable factor that contributes to ending dissociative thoughts is reportedly someone distracting them by talking to them directly (Černis, Freeman & Ehlers, 2020). During the recovery phase, the person might feel shame, frustration, or resentment toward mental healthcare workers or family members for the events that led up to treatment (Cullberg, Skott & Strålin, 2020).

Symptoms experienced during a psychosis can vary, but the most common include delusions, allusions, hallucinations, destructive thoughts, and negative symptoms. Delusions come from an inability to properly interpret an event (Cullberg, Skott & Strålin, 2020). Allusions refer to events that have transpired but have been misinterpreted to mean something else (ibid.). Hallucinations, most commonly auditory, are when a person experiences sensations that do not come from the world around them (ibid.). Destructive thoughts refer to thoughts that disrupt a

normal thought pattern, often leading to stunted or unintelligible trains of thought to the listener (ibid.). Negative symptoms encompass all forms of symptoms that lead to withdrawal, passivity, or a lowered response from a person.

Risk factors for falling into a psychosis range from genetics, childhood experiences, trauma, and stress (Černis et al, 2020; Cullberg, Skott & Strålin, 2020). While it is difficult to pinpoint the exact reason a psychosis or serious mental illness occurs, there are proven safeguards that can lessen the risks and consequences of a psychosis, and the largest safeguard is a solid social network, often made up of supportive family members and friends (Cullberg, Skott & Strålin, 2020). Even so, the rate of a psychotic relapse is upwards of 70% within five years amongst those suffering from mental illnesses associated with psychotic episodes (Castle & Gilbert, 2003). This indicates that even with a consistent level of compliance to treatment, relapse of psychotic episodes is more common than not (Castle & Gilbert, 2003). Family members, alongside a sense of purpose (Antonovsky, 2005), and a career are some of the safeguards that protect a person with a serious mental illness from repeated psychoses. Medication and regular contact with mental health professionals is also a factor that can prevent future psychotic episodes.

3.4 Defining the role of the caregiver

There are many terms associated with the role of informal caregiving. In the process of this research, I have found many terms to represent roughly the same concept of this role with slightly different connotations. Some commonly used phrases include caregiver, caretaker, key relative, relative, and primary caregiver (Beydoun, Nasrallah, & Sabrah, 2019). For purposes of clarity, I have chosen to use the term informal caregiver while referring to all forms of informal caring, meaning a person in a caregiving position without a professional connection to the person with a diagnosis. This most often refers to a relative or spouse of a person but in some cases can include a friend.

A formal caregiver is defined as a healthcare professional such as a nurse, doctor, or social worker (Beydoun, Nasrallah, & Sabrah, 2019). The main difference between formal caregivers and informal caregivers is a salary and some form of formal training (ibid.). Informal caregivers may receive some form of education related to caring for a family member or friend, but this

is not requisite to the role of informal caregiver. Expectations of the role of caregiver vary. For some, caregiving entails holistic care, meaning going beyond the physical needs and fulfilling mental, emotional, and spiritual needs as well (Hermanns & Mastel-Smith, 2012). For others, a more straight-forward definition of caregiving can mean simply actions carried out on behalf of someone else (ibid.). There is a wide range of expectations between these definitions. This inconsistency of expectations often leads to confusion and frustration on the part of the caregiver, the formal caregiver, and also the person receiving care. An informal caregiver fulfilling the expectations of both the formal caregivers and the person receiving care is a goal that is most likely unattainable.

4. Previous Research

The following collection of studies focus on the different aspects of the role of caregiver that have been previously explored. Important fields of research include studies related to the experience of caring for a person with a serious mental illness, the study of the role of caregiver (not necessarily limited to mental illness), the study of support levels for families provided by mental health professionals, and the study of resilience in relation to caregivers. These areas of research give insight into the reality that is caregiving for a family member with a serious mental illness. While the research in these areas provides engaging recognition of these peripheral topics, the intention of this study is to incorporate elements from all of these respective areas.

4.1 Relatives: caring for a family member with a serious mental illness

Previous research suggests that the lives of relatives of family members with a serious mental illness become intertwined with the lives of those living with a serious mental illness. A 2012 Norwegian mixed method study including questionnaires, interviews and focus groups of relatives of family members living with a serious mental illness as well as mental health nurses concluded that the lives of these relatives are severely affected by their family members (Weimand, 2012). This study also found that the majority of interactions with mental health professionals were perceived by relatives as negative experiences (ibid.). Due to the nature of the relationship, relatives' lives are often equally altered in the face of changes of a family member living with a serious mental illness (ibid.).

The role of caregiver to someone with a serious mental illness often leads to added stress. A major study conducted in the United States in 2019 concerning the intensity and duration of caregiving to a family member living with severe mental illness found that caregivers of this sort had poorer health than the general population (Barnhart et al., 2020). Stigma surrounding mental health also led these caregivers to withhold sharing the mental state of their family members with others as a form of unburdening themselves (ibid.). The authors of this study

described the negative effects that are associated with this form of caregiving as a “major public health concern” (Barnhart, et al., 2020 p.7).

A 2019 quantitative study comparing the burdens of being a caregiver to a person with schizophrenia to being a caregiver to a person with treatment-resistant schizophrenia found that caregivers of persons with treatment-resistant schizophrenia experienced a significantly higher amount of stress, anxiety, stigma, as well as health issues (Velligan et al., 2019). Treatment-resistant schizophrenia is defined as resistant to two or more antipsychotic medications for more than a six-week period and this occurs in roughly one third of patients with schizophrenia over time (ibid). While treatment-resistant schizophrenia does not make up the majority of schizophrenic cases, it does illustrate the potential added burdens of caregivers that have difficulty encouraging their family members to receive treatment due to the nature of the illness; that being an inclination towards paranoia, suspicion, and resistance to treatment at times. The elevated levels of stress, anxiety, and stigma only illustrates how much more burdensome this experience can be with family members not receiving effective treatment, which is already considered to be a remarkable burden in and of itself (ibid.).

These studies illustrate a distressing pattern of strain placed on the caregiver of a person with a serious mental illness. Results of these studies indicate that caregiving in relation to mental illness causes stress and impedes recovery from formal systems of care.

4.2 The role of the caregiver

A 2012 study from Cyprus aimed to find how informal caregivers of cancer patients coped (Papastavrou, Charalambous & Tsangari). After recruiting 130 participants through contact with cancer patients and identifying primary caregivers, the participants were given a questionnaire that encompassed three areas of data (ibid.). The three areas included the caregiver’s subjective opinion of their family member’s health, the caregiver’s main source of support, and the information provided by physicians and staff (ibid.). Results from this study suggest that the majority of informal caregivers coped through emotional strategies such as hoping for a miracle or searching for hope through religious means (ibid.). Depression is prevalent amongst informal caregivers of cancer patients and they employ various coping strategies in order to manage from day to day (ibid.).

Another study related to caregiver strain experienced by American legal guardians (foster, biological, or adoptive) of youth receiving care from a mental health system has attempted to differentiate between internal strain and external strain (Fawley-King et al., 2020). The study defines internalized strain as worry or guilt and externalized strain as anger and resentment (ibid.). A survey was conducted on 1,828 caregivers with results indicating that adoptive and foster caregivers experienced less internal strain than biological parents and there was no statistically significant difference between the groups with externalized strain (ibid.). Both groups reported a higher level of stress than parents without a child in the mental healthcare system (ibid.). The results of this study indicate that biological parents feel a greater strain because they are more likely to blame themselves for the mental health problems of their children, and moreover, they are more likely to feel internalized strain due to the fact that they anticipate dealing with these problems for the rest of their lives (ibid.).

A Swedish study (Almberg, Grafström & Winblad, 1997) surveying and interviewing 52 caregivers of elderly patients diagnosed with dementia was carried out with intentions to measure burnout levels and of caregivers and what the underlying causes could be. Burnout, according to these researchers, is indicated through a person experiencing a state of physical, emotional, and mental exhaustion due to strain (ibid.). The researchers argue that there has been extensive research on burnout of professionals working with dementia patients but not on caregivers. Through regression analysis, the study found that limited social networks, poor health, and lack of a positive outlook were the three most significant variances of caregivers experiencing burnout (ibid.). The burnout rate also indicated that a familial connection and which role the caregiver is in relation to the patient (wife, daughter, friend etc.) influences the expectations of care placed on the caregiver (ibid.). Wives and daughters experienced the highest rate of burnout, possibly due to expectations placed on them because of their gender and the greater emotional burden they place on the level of care required (ibid.). This indicates that the person's view of the role of caregiver influences the rate of burnout.

These studies show that coping strategies of caregivers often take the form of searching for a positive outcome in the future. The different forms of strain that can affect caregivers are influenced by the nature of the relational attachment. Caregiver burnout rate is also affected by the expectations placed on the caregiver.

4.3 Inadequate support for families from mental health professionals

Interactions between mental health professionals and relatives of people living with a serious mental illness often result in tension. A Swedish study of professional views on how to support relatives of people with a serious mental illness found that mental health professionals are often aware of how important support to these relatives is but find it difficult to provide adequate support due to a lack of understanding of the support systems in place, a lack of confidence in being able to provide support properly, and finally, that cooperating with relatives is often very beneficial but ultimately difficult to achieve (Hjärthag et al., 2017).

The stigma of living with a serious mental illness is often felt by association of those in a caretaking role. Affiliate stigma, also known as courtesy stigma in some studies, is the stigma of being related to or associated with people living with a serious mental illness (Zhang et al., 2018). Affiliate stigma relates to the internalization of societal stereotypes and misconceptions of what can cause a serious mental illness (ibid.). A recent quantitative survey study in Singapore analyzed the connection between affiliate stigma perceived by those in a caretaking role of someone with a serious mental illness and the measure of quality of life. Results of this study found a correlation between high levels of stigma with poorer quality of life measures (ibid.). Another finding from this study was that parents experienced higher levels of affiliate stigma than other caretaking roles such as siblings or spouses.

These studies illustrate how cooperation between formal caregivers and informal caregivers can be difficult on the part of formal caregivers due to a lack of supportive training in this area. Affiliate stigma experienced by caregivers of people living with a serious mental illness also contributes to a difficulty receiving adequate support from outside networks.

4.4 Resilience of relatives

As previous studies have shown, the role of caregiver to a person with a serious mental illness often results in unexpected forms of resilience (Szmukler et al., 1996). This begs the question of how it creates this resilience in this group specifically and in what ways is this group able to adapt to challenging situations over longer periods of time.

In order to measure the experience of caregiving, this 1996 study attempted to create a self-report measure of the experience of caring for someone with a serious mental illness (Szmukler et al.). The experience of caregiving inventory (ECI) was created by and measured on caregivers of relatives with a serious mental illness (ibid.). As anticipated, caregivers experienced negative symptoms such as elevated levels of stress, stigma, and difficulties in interactions with services amongst other things (ibid.). A surprising result of this study was that there were also positive results that the researchers had not predicted. The positive effects of the being a caregiver to a person with a serious mental illness often resulted in the mastery of coping effectively under difficult circumstances, resilience, optimism, and a strong familial connection (ibid.). The significance of this finding led the researchers of this study to warn that mental health professionals should fight the urge to “pathologize” the role of caregiver as purely a burdensome role (Szmukler et al., 1996 p.147).

Resilience in children has been studied extensively but fewer studies have been conducted on the role resilience plays as an adult relative of a person with a mental illness. An integrative survey study by Jaclene Zauszniewski, Abir Bekhet, and Jane Suresky in 2010 reviewed studies that related to the concept of resilience. The study focused on the main tenets of resilience which they pinpointed as acceptance, hardiness, mastery, hope, self-efficacy, sense of coherence, and resourcefulness (Zauszniewski, Bekhet & Suresky, 2010). The outcomes of this study suggest that resilience indicators are often likely to predict the quality of life of relatives in a supporting role of a family member with a serious mental illness (ibid). Furthermore, these resilience indicators may not only prevent common negative factors associated with caretaking, but they may, in fact, enhance the quality of life of caregivers (ibid).

It is commonly understood that the role of caregiving is burdensome. These two studies have shown that there are positive aspects of caregiving that contribute to attributes of resilience. These aspects of acceptance, mastery, hardiness, and resourcefulness are recurring themes in this study as well.

5. Theoretical guidance

5.1 Introduction

In order to gain a more refined understanding of what being a caregiver to a family member with a serious mental illness means, two theories were used to sharpen the representation of what this particular role involves. The two theories used in this study are Robert Merton's role-set theory (1957) and Adrian Van Breda's theory of resilience (2011). Merton's role-set theory (1957) gives a fundamental understanding of how a role such as caregiver can influence a person's actions and abilities to maneuver within and around the boundaries and limitations placed on him or her. Van Breda's theory of resilience (2011) deconstructs the preconceived notions of where resilience comes from and how it grows in unusual and challenging circumstances.

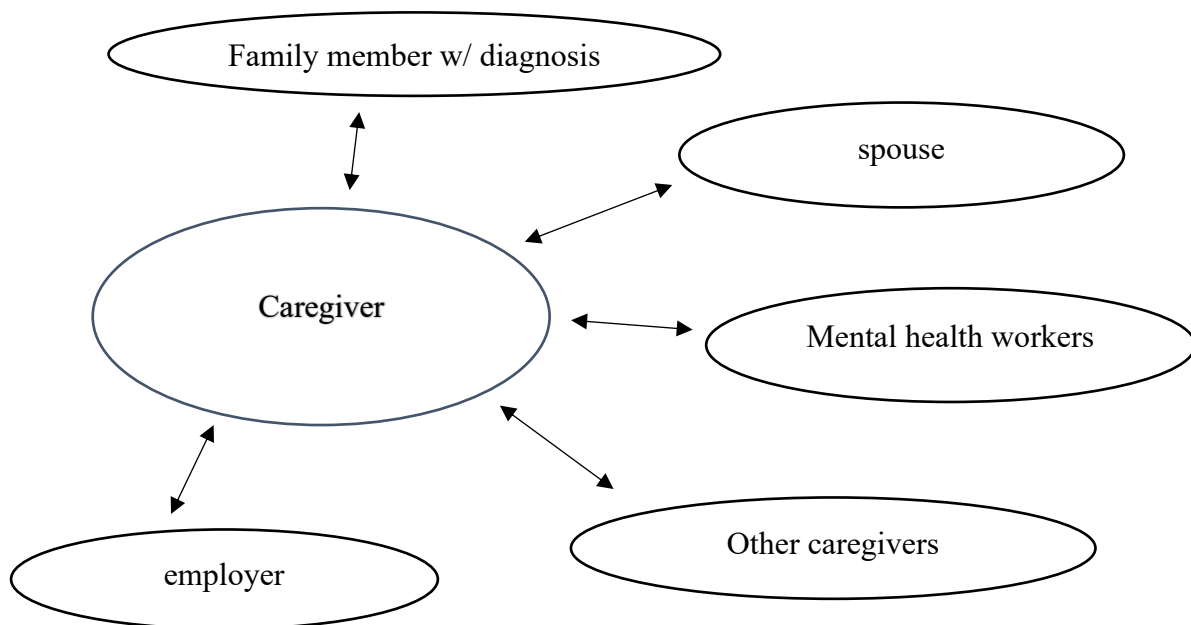
5.2 Role-set theory

Robert Merton's role-set theory (1957) stems from his discussion of the theories of the middle-range. That is, sociological theories that attempt to understand a specific function in society instead of grand and sweeping theories that attempt to justify all of human interaction. Instead, Merton (1957) attempts to answer how a role functions in relation to itself as well as other roles it comes into contact with. Through this middle range theory, Merton implies that we can infer meaning on greater levels through clarification of a smaller model (1957). For instance, Merton uses Gilbert's theory on magnetism to explain how a specific theory can have consequences throughout the greater scientific world simply by attempting to answer one specific question, and through this, other answers can be accessed (1957).

In order to understand Merton's role-set theory, it is important to first define the term *social status* and how this is different from *role*. A social status, according to Merton (1957), is defined by a person's gender, race, sexual orientation, profession, and age. A social status is ascribed, which means the person has had no choice in this status, such as age, gender, or race. An achieved status occurs through effort, profession, or becoming a parent. That is to say that

an achieved status can be controllable. A role, on the other hand, describes one aspect of that person's status, such as a teacher, mother, or caregiver. Within one role, there is a set of behaviors, obligations, privileges, and expectations that follow each interaction with other roles. As an informal caregiver, Merton's (1957) theory helps to explain how different expectations can be placed on a person as well as how expectations move outwardly towards others as well. An example of the interactions that can stem from one role of caregiver may look like the following model:

5.2.1 Role-set model



What this model illustrates is that there is a complex relationship within just one role of a person's life. Interactions between these roles provide unique challenges and expectations placed on one another. A role is based on a sort of performance between two parts: a teacher cannot teach without a student and a caregiver cannot give care without a person to care for.

5.2.2 Role Conflict

While there are differing ideologies amongst theorists regarding how role theory should be defined in specific terms, there is a consensus that role-set theory circles around the concepts

of characteristic behaviors, parts that should be played, and the expectations that follow (Biddle, 1986). Expectations create the bonding factor that makes up the role-set. Expectations go back and forth between parts and can alter or stabilize the relationship, depending on how well the expectations align (Biddle, 1986). When expectations do not align, *role conflict* arises. *Role conflict* is created when a person is subject to conflicting pressures within his or her roles (ibid.). *Role ambiguity* may also occur when the expectations on the role are incomplete or insufficient (ibid.). Another form of role conflict is *role overload*, meaning a person has been given too many expectations to manage (ibid.). All of these forms of role conflict lead to people creating coping behaviors in order to manage incompatible expectations (ibid.).

The three types of responses to role conflict according to Donald Hall (1972) are as follows; restructuring the external expectations placed on a person's position, redefining a person's own perceptions and expectations of his or her own role, and finally, attempting to meet all expectations. These three strategies allow for the person to attempt coping with role conflict while maintaining some form of control over his or her role (Hall, 1972).

5.3 Resilience theory

Resilience theory in social work is described as the ability to not only cope with difficult situations, but to thrive and grow (Van Breda, 2011). While resilience is often loosely defined, Van Breda (2018) attempts to narrow down a definition to its core, which he later identifies as the relationship between vulnerability and negative outcomes with a person. While negative outcomes and vulnerability have a tendency to damage a person, in some cases this results in a repairing and strengthening effect. Other definitions of resilience view the term as a process instead of an outcome, choosing to focus on the internal workings of the individual instead of the end result (Van Breda, 2018).

The ability to judge resilience based on a sliding scale instead of a have-or-have not model allows for resilience to be viewed as a muscle that can be strengthened instead of an innate quality (Van Breda, 2018). Resilience researcher Ann Masten (2018) defines resilience for scalability as follows; "the capability of a system to adapt successfully to significant challenges that threaten the function, viability, or development of the system" (p. 16). Resilience is often studied in relation to family systems in order to understand trauma on a larger scale such as

war, natural disasters, or the effects of insecure attachment at a young age (ibid.). There is significantly less research on resilience in relatives of people with a severe mental illness. This theory is therefore applicable to this study because it offers causation of where these informal caregivers gain strength and grow where others may not.

Determinations of ‘good’ or ‘bad’ outcomes can also define resilience. By the individual’s ability to alter expectations in the face of adversity, an otherwise ‘bad’ outcome can become a relatively ‘good’ outcome from the perspective of a resilient person. This focus on positivity in the face of hardship is one of the main arguments that Van Breda (2018) makes in the specific case of social work. Social work, he argues, is a profession driven by the forces of social change and betterment. Most social work theories focus solely on the understanding of vulnerability and negative outcomes as a force of harm (ibid.). While this may be true in many cases, there is value in trying to understand the mechanisms of those that are capable of taking vulnerability and negative outcomes and creating a positive force from that.

Masten (2018) identifies promotive and protective processes amongst those that show high levels of resilience. These factors include individual attributes such as problem-solving skills, self-regulation skills, mastery of motivation, as well as relational attributes such as a secure attachment in relationships starting in childhood and carrying through to adulthood (Masten, 2018). A parent’s role, Masten argues, is critical in protecting children from overwhelming amounts of stress. In resilience research, it is also important to note that smaller amounts of stress for children are critical in building life skills and learning to manage stress in the long term, just as children need exposure to some illness in order to build up immune systems (ibid.). Resilience among relatives of people with a serious mental illness are exposed over longer periods of time to stress and adversity.

A criticism of resilience theory is that it can be exploited by certain agendas in order to make the argument that individuals have the power to create their own outcomes with the help of resilience, thus making the conclusion that welfare systems should not be necessary (Van Breda, 2018). Van Breda (2018) counters this argument by highlighting the research on resilience that points to higher levels of resilience amongst those who have had solid relationships built through childhood and further into adulthood. This, he argues, is a result of being able to rely on a support network in critical times of need. It is therefore important to resist the temptation of labeling resilience as an individualistic quality. Resilience, according

to Van Breda (2018), is also a non-renewable form of energy and should not be glorified as a miracle cure to adversity. The expenditure of resilience takes a toll over time on caregivers and should therefore be seen as a valuable characteristic that is not to be exploited by social services and mental healthcare systems.

6. Methodology

6.1 Methods of data collection

The research methods of this study consisted of a content analysis of data gathered through qualitative interviews. With the use of an abductive theoretical approach, the study was analyzed and assessed based on the data as well as use of Merton's role-set theory (1957) and Van Breda's theory of resilience (2011).

6.1.1 Interviews

The study was conducted through semi-structured interviews with a total of six participants. After consideration of the area of interest, I conducted a pilot interview and simultaneously collected data through an online forum related to family members of people diagnosed with a serious mental illness in order to determine which method would more appropriately suit the study.

6.1.2 Selection of participants

Purposive sampling methods were used in this study (Silverman, 2010). Initial methods of data collection led me to search for participants that have family members with a diagnosis of either schizophrenia or bipolar disorder. The underlying points of interest with both diagnoses are elements of paranoia and a difficulty with self-assessment in the midst of psychotic episodes/manic or depressive episodes (Lindqvist, 2012). The purpose of this study is not to compare these diagnoses but instead to examine how these two key factors shared by both schizophrenia and bipolar disorder have an impact on caregivers specifically. A variation of sampling was attempted through contact with both organizations and Facebook support groups for family members of both bipolar disorder and schizophrenia. All participants willing to take part in this study except one had or have a family member with schizophrenia. One participant, Kent, was married to a woman with bipolar disorder. While this may appear to be uneven in variation, the most essential elements of paranoia and a difficulty with a self-assessment of the

diagnoses, remains in all candidates for the study. All participants of this study have experience with a family member with a serious mental illness involving elements of paranoia and difficulty seeking treatment in some form or another.

6.2 Methodological approach

The methodological approach taken in this study was a content analysis by use of an abductive process. A content analysis consists of determining categories within the data and systematically connecting them to a pattern (Silverman, 2010). Using an abductive approach, meaning the use of the process of elimination through alternation between both theory and data in order to come to the most plausible explanation (6 & Bellamy, 2012), the design of this study relied heavily on a staggered review of the data as well as the theories that emerged as most fitting. That is to say, the results of this study emerged through a thorough grasp of both the data collected as well as theories presented without a formal order, as would be the case with a deductive or inductive approach.

From an epistemological standpoint, this study has taken a relativistic approach. Relativists see knowledge as conditionally responsive to context, perspective, and theory (Eliasson-Lappalainen et al., 2008). Another definition of relativism is seen from a position that everything is subjective and connected to a person's understanding and therefore dependent on that person's situation and all of the limitations that apply to that individual (Allwood & Erikson, 2012). As the designer of this study, it is therefore limited to my knowledge and my limitations. The foundations of my knowledge are also built on all of the research that has gone before me. The experiences in my life, including family members with mental illness, have pushed my curiosities and understanding of what a caregiver can be and how mental illness impacts a relationship. While my experiences are valid, they are not identical to others in my position and I have had to distance my assumptions throughout the research process. The goal of this study has been to answer qualitative questions of how a caregiver utilizes strategies with a family member with a serious mental illness. In order to accomplish this, I have had to define what a caregiver, strategy, family member, and serious mental illness mean through my own perspective.

6.2.1 Reflexivity in research

According to Charlotte Aull Davies (2005, p.6), the purpose of research is to mediate between different constructions of reality. Mediation requires both communication and an ability to remove oneself from a narrow scope of vision in order to assess the larger picture. Reflexivity is defined by Davies as "turning back on oneself, a process of self-reference" (Ibid., p.4). The researcher uses reflexivity to extend the peripheral observations in the field to observe and think critically on his or her own role in the context of the field of research. Reflexivity and objectivity are therefore dependent on one another (ibid.). Reflexivity has played an essential role throughout the entire research process, not just during interviews. Rennstam and Wästerfors (2015) state that the theorizing process is dependent upon the researcher's ability to reflexively process the data. As the interviewer, I make up one half of the interview process. It has therefore been an important aspect of my research to reflect on my own role and the part I play in the methods of data collection. As an American that grew up and is familiar with the American healthcare system, I am accustomed to how the mental healthcare system functions there. Three of the participants are American and have/have had experience exclusively with how the mental healthcare system works in that context. Living in Sweden for the past 12 years, I also have experience of how the healthcare system works here. A limitation I have experienced from this is that of lacking an understanding of how the mental health system has functioned previously in Sweden and a lack of understanding of how the mental healthcare system functions currently in the United States. It has also been a challenge not to compare the systems, meaning it would be easy for me to assume that the experience of one country would be similar to another.

As a social worker, my contact with different agencies relating to mental health and how the system operates in Sweden has been on a professional level. My experience with mental healthcare in the United States has been from the point of view of a family member. My experiences are therefore limited in both countries. With three of the participants describing their experiences in Sweden and three in the United States, it has been beneficial for this study to have knowledge of how both systems function. This is not to say that there is an element of comparison between countries, rather, there are similarities despite varying organizational and cultural differences in each respective country.

6.3 Research strategy and design

The initial strategy for this study was to explore the dynamic of caregiver in relation to a serious mental illness. My curiosity focused mainly on what differentiated informal caregiving involving mental illness from informal caregiving to other illnesses. The strategy from this point led to a broad search spectrum. A search for previous research related to this topic included an overview of the topic of mental illness and the role of caregiver. With help of Lund University's library network LOVISA, the online library resource LUBsearch, and Google Scholar, I searched for information with key words such as 'mental illness', 'family member', 'schizophrenia', 'bipolar disorder', 'caretaker', 'caregiver', and various combinations of these search words.

The pilot interview was conducted early and provided an abundant amount of compelling data. Areas of interest that emerged from this interview included coping strategies and mechanisms for overcoming long-term hardship. This led to further interviews more narrowly focused on these areas and previous research related to these areas. Specific key words included 'caregivers + mental illness', 'caregiver + role', and 'caregiver + burden'. Findings of one of the studies conducted in 1996 (Szmukler et al.) showed a surprising result of resilience found in informal caregivers of people diagnosed with a serious mental illness. This finding led me to pursue the themes of resilience in my interviews. I also researched the area of resilience as a theory (Van Breda, 2011). Discussion of the role of caregiver led to Merton's role-set theory (1957) in order to wholly interpret the dynamic of how the role of caregiver leads many to develop resilient tactics.

Three interviews were carried out in person at the homes of the participants and one came to my home for an interview. Due to the unforeseen challenge of Covid-19, I made the decision to recruit the last two participants through a forum dedicated to support for family members of people diagnosed with schizophrenia as well as a Facebook support group for family members of people diagnosed with bipolar disorder. I was unable to recruit any participants through the bipolar support group. Two participants, Sandra and Jackie, were recruited through the schizophrenia forum. Both participants live in the United States, so we decided to do telephone interviews via Skype.

Three of the interviews were conducted at the homes of the participants and one interview took place in my home. Two interviews were held via telephone due to the participants living in the United States. The interview style was a semi-structured format with opportunity to ask follow-up questions. My aim was to allow all participants to share their answers freely and without interruption. It was of importance to allow all participants to freely communicate their experiences in their own words. All interviews spanned between one to two hours and they were recorded for purposes of transcription. The transcribed interviews generated 98 pages of material.

6.3.1 Interview guide

The initial interview guide (see appendix A) was designed for the pilot interview. The questions related to background information, strategies implemented by the relative in order to maintain a relationship with the person diagnosed with a serious mental illness, and what frustrations or regrets the person might have had throughout his or her relationship. After the initial interview, the interview guide became more loosely structured and focused more on appropriate follow-up questions for the participant. The reason for this was to give the participant the freedom to tell his or her story in his or her own way without redirecting to another topic. The interview guide was further adjusted after the first four interviews due to an emerging theme of resilience and the role of caregiver. This narrowed the focus of questions to topics of resilience as well as the role of ‘caregiver’ in relation to mental health professionals.

6.3.2 Recruitment of participants

After an initial pilot interview with a person I met through an organization unrelated to mental illness, further participants were recruited through organizations that support family members of people diagnosed with a serious mental illness in Sweden. After contacting the chairperson for three local organizations, three participants reached out to me with interest in participating. The remainder of the participants have been recruited through a forum post on a website dedicated to offering support to family members and relatives of people diagnosed with schizophrenia. A total of six participants were recruited and two people were considered for the study but were unable to participate. One person had a serious mental illness as well as

other family members and I considered that to be challenging the ethical standards of this study I and decided against her participation. Another person contacted me to take part in the study but did not meet the requisites of a caregiving role. The empirical data collected is shown in the following table.

6.3.3 Table 1. Empirical data

Name	Relationship	Country
Björn	Father to a son with schizophrenia	Swe
Sandra	Mother to a daughter with schizophrenia	USA
Thomas	Father to a son with schizophrenia	Swe
Jackie	Mother to a son with schizophrenia	USA
Kent	Former husband to a wife with bipolar disorder	Swe
Becka	Daughter to a father with schizophrenia, both parents deceased due to mental illness	USA

6.4 Measures of research quality

6.4.1 Reliability

Reliability in this study can be measured by how accurately and diligently I have conveyed the words of the participants in this study (Silverman, 2010). In order to ensure accuracy, I recorded all interviews with informed consent. After each interview was completed, I transcribed the interviews into text form. The first two interviews were transcribed with the help of a transcribing service called Happy Scribe. After careful reading and listening to the audio for errors, I decided to transcribe the rest of the interviews without a transcription service to ensure accuracy without the time-consuming process of double checking for errors. Three of the interviews were conducted in Swedish and transcribed in Swedish. Only citations were translated from Swedish to English. As a native English speaker and fluent in Swedish, I translated all texts myself. In cases where a direct translation would not be clear, I have chosen words or phrases with the closest likeness to the meaning of the original Swedish.

6.4.2 Validity

The validity of this study is a measure of how accurately I have answered the questions presented in this study, that is to say, a determination of if this study answered the questions I have put forth (Silverman, 2010). In order to ensure that I have fulfilled the objective of this study, I have considered the key questions in relation to the data resulting from the interviews and I have been open to amending the phrasing of these questions in order to accurately be able to answer them in a substantive manner. As to the accuracy of what is said during the interviews, this was a study of the perspectives of informal caregivers, I do not address the accuracy of how correct their representations may be. How they choose to describe their experiences is what I have chosen to portray through data.

Interviews provided the most fitting medium for this study because of the opportunity to ask specific questions as well as follow-up questions (Silverman, 2010). This would not be possible with a document analysis because I would not have the option of asking specific questions. I would also have limited access to background information of those posting and responding to threads on forums related to mental illness (Meeuwisse & Swärd, 2008). I briefly considered a method of survey for data collection but decided against this method. Surveys require a solid foundation of inquiry from the early stages (Silverman, 2010), meaning I would have had little flexibility in the later stages of the study for adjusting questions to best suit the direction that the study had taken. Through the process of interviewing, themes and patterns emerged which allowed me to alter my interview guide to better fit these themes. Interviews allowed for participants to describe the most compelling and dominant elements of caretaking in their own words.

The validity of measuring the concept of resilience is not put forth in quantitative terms, rather, in terms of Van Breda's (2011) most basic understanding of resilience, which he defines through an assessment of vulnerability and negative outcomes. I have not taken on the task of determining whether or not the participants have shown true resilience or, instead, giving off the appearance of resilience. Resilience has instead been measured by what Masten (2018) refers to as the scalability of resilience. In this study I view resilience in terms of an exercise that is performed through small stressors that build up a tolerance for the burdens of caretaking.

All of the participants in this study have shown signs of resilience. This could lead to the conclusion that the results have been skewed through the selection process. I argue that contrary to this idea, all participants have been recruited through forums and organizations providing support and outreach to informal caregivers. This suggests that all participants struggled with the role of informal caregiver at some point throughout this process.

6.4.3 Generalization of data

This study does not attempt to generalize a representative sample of all caregivers to family members with a serious mental illness. Instead, this study attempts to observe the data represented from this purposive sample in order to infer behaviors by searching for the qualitative value of broad representation. These participants represent a wide range of variables in connection to their family members. From relationships representing a parental bond, a child to parent bond, and marital bonds. Participants vary in age, gender, socio-economic background, and ethnicity. This study is by no means searching for comparative components. A wide variation of all factors has shown that despite all of these possible disparities amongst the participants, they have all shown remarkably similar strategies in managing their circumstances.

While this study has focused specifically on the experiences of informal caregivers to people with a serious mental illness, the terms and phrases that were generated in this study can be applied to other areas of interest. The terms such as recalibration, identity guardian, and ally can also be applied to other caregivers managing a stressful situation. Family members of relatives living with dementia, cancer, and other long-term illnesses that require care most likely experience similar scenarios in which these roles would manifest.

6.4.4 Unforeseen Challenges

Due to the outbreak of Covid-19, it was required to limit contact and travel on public transport which meant all meetings with my advisor were carried out remotely in order to safely stay in contact without the risk of catching or transmitting the virus. In person meetings were replaced with video calls. Avoiding public spaces also led to fewer trips to the library and more searches for resources available online. As previously mentioned, I was no longer able to recruit more

interviews in person which led to telephone interviews as a replacement. Not being able to see the person face to face can be seen as a detractor. I do not see this a detractor because telephone interviews may allow for a person to speak more freely by removing a layer of intimacy within the conversation that may hinder some from speaking openly about sensitive issues. I did not determine the telephone interviews to be of a lower standard of quality in comparison to face to face interviews.

6.5 Ethical considerations

Interviews of first-degree relatives of people living with a serious mental illness come with ethical concerns such as delving into sensitive topics that might cause distress (Ryen, 2016). With this in mind, interview candidates consisted of adults that have been recruited through some sort of network that provides support for relatives of people living with a serious mental illness. In accordance with the four principles of ethical research from the Swedish Research Council (Vetenskapsrådet, 2020), written and informed consent was a requirement for this study. Conformed consent requires that the participant understands that they are being researched, the nature of the research, and that they have the right to withdraw their consent at any time (Ryen, 2016). Confidentiality was assured through anonymity of names and locations. All participants were informed of their right to withdraw consent and participation in this study at any time. Participants have also been informed that the purposes of this study are for research only and all information gathered through interviews and contact will not be used for anything outside of this study.

Balans, Schizofreniförbundet, and RSMH (Riksförbundet för social och mental hälsa) offer support for both people living with a serious mental illness and relatives in Sweden. Contact through these organizations better assured that I would come into contact with relatives that self-identify as this target group and they are actively working through the challenges through outreach, thus lessening the ethical concerns of causing distress. There are still remaining ethical concerns with interviews. The interview process may motivate the participant to share difficult periods related to stressful or traumatic events, which could lead the participant to re-experience trauma. In order to lessen the chance of causing distress, the questions in my interview guide have purposely been designed to let the participant answer freely and on their

own terms. The semi-structured design of the interview guide allowed the participants to share, give examples, or avoid topics that might be too sensitive or troubling to discuss.

Another ethical challenge of this study is that I have received consent of all caregivers, but I have not been granted formal consent of the family members with a diagnosis. In one case this would not be possible as the family members have passed away. In four other instances, caregivers informed their family members that they would be participating in this study. This provided assurances that the majority of family members have been informed and cooperative towards this study.

A potential risk for interviews in social work research is that the nature of this profession is to come in contact with people who are already in a vulnerable state. The participants after recruitment have willingly offered up their stories and have been highly motivated and enthusiastic about the importance of sharing these experiences. All of the participants contacted me of their own volition and all participants expressed a need for more research and attention to this topic. This motivated willingness to participate assured me that the ethical risks of reopening past trauma were minimal.

For purposes of anonymity, all names and locations have been changed during the transcribing process. The ages of the participants have not been shared, partially for reasons of maintaining anonymity and partially because their stories occur over a span of many years. Listing the ages of the participants runs the risk of having the reader fasten to an idea of a participant at a certain age when, in fact, participants' accounts span the course of a lifetime.

6.6 Methods of analysis

My methods of analyzing the material began with the initial pilot interview. In order to assess the viability of the study done through interviews, I needed to begin thinking in terms of understanding the material. This was done by sorting through the transcripts of the pilot interview and searching for key patterns and behaviors that connected to the role of caregiver. Analysis was also a part of the transcription process because of the time-consuming nature of transcription. The many hours spent transcribing allowed for close reading of the material. After themes and patterns emerged, I read through all material again and coded all interviews

for eight possible themes. The material was analyzed through Rennstam and Wästerfors' (2015) method of sorting, reducing, and arguing. Sorting through the material allows for a structured method of retrieving relevant data (ibid.). Reducing the material consists of finding the most compelling and applicable citations (ibid.). In order for these citations to fittingly argue my thesis, I have structured the findings in the form of the 'excerpt commentary unit' (ibid.).

My initial form of coding consisted of an open and quantitative gathering of all relevant citations that are representative of a theme. After this, a more selective form of coding was used to find the most qualitatively relevant citations that represent each theme. Interpretation of the data did not begin until the theories of role-set and resilience (Merton, 1957; Van Breda, 2011) were established. This was done by reviewing the patterns in the data and a review of sociological theories that could best illustrate the underlying processes that lead to these patterns in the data.

Interpretation of qualitative data is a process that involves motivating the significance of a set of gathered material (6 & Bellamy, 2012). As a researcher of qualitative data, I am searching for subjective meaning in material. A subjective approach to analyzing material leaves an opening for doubt and uncertainty, which is why I anchor my data in established theories. Selected texts are direct quotes from interview participants. I have chosen to use longer citations in order for the reader to interpret the data from a larger context, which is usually provided by the participant. This makes for longer reading but this method adds value to the study by providing the material in the context the participant gives in his or her own words. This method also ensures the integrity of the participants so the risk of their quotes being taken out of context is minimized.

7 Findings

The results of this study led to an emergence of strategies used by caregivers of people diagnosed with a serious mental illness. In my analysis, I show that these strategies lead caregivers to manage role conflict that arises out of the strain of being a caregiver. As a result of these strategies, the participants form a type of resilience in the face of long-term care that makes the conflicting roles manageable. In the first part of this chapter, quotes from the interviews are used to represent how these strategies manifest amongst caregivers in relation to the people diagnosed with a serious mental illness. Another dominant theme that surfaced from the data is the way caregivers take on roles and present themselves in different contexts. The second half of the chapter explains how different roles reveal themselves in the face of formal healthcare systems. I explore the way caregivers maneuver through critical elements of care, including managing the role of having expert knowledge of a family member, protecting the identity of a family member, and adapting to mental healthcare systems.

7.1 Management strategies for living with a person with a serious mental illness

Through these interviews, different management strategies emerged in order to be able to cope with living with a person with a serious mental illness. The four most common management strategies were as follows; (1) upholding the established roles of each person in order to maintain a clear understanding of which person is playing which part, (2) recalibration of expectations, which consists of adjusting levels of expectation for the family member in order to maintain a positive outlook on the situation, (3) differentiating the person from the illness, meaning the caregiver actively separates the symptoms and actions associated with the diagnosis from the family member, and lastly, (4) indulging in the scenarios that are most beneficial to the situation at hand, even if that entails playing along with a delusion that can for a professional be considered unethical. These strategies were used by almost all of the participants in various ways but with the same motivation, that being to minimize the tension and stress between parts. In role-set theory, these strategies are used to manage a form of role conflict that arises from an untenable set of expectations placed on the two parts (Biddle, 1986). In order to resolve these role conflicts, caregivers find ways to alter expectations.

7.1.1 Upholding roles

This study revealed a pattern of what I refer to as upholding roles. This term refers to the active maintenance of defining roles outside the diagnosis, such as mother, father, daughter etc. The concept of upholding roles allows for each person to play their part in order to maintain a clear understanding of the expectations placed on each person. In order for these roles to be upheld in an otherwise unencumbered relationship between family members, each person plays his or her part in relation to the established expectations placed on the role of mother, father, son, daughter, husband, and wife. In a relationship where a serious mental illness plays a third role in the dynamic, upholding established expectations can be especially important in order to maintain some semblance of normalcy.

The role of the parent can be a difficult one to maintain when a child is diagnosed with schizophrenia. Björn and his wife struggled with their son Anton's schizophrenia diagnosis when Anton was a teenager. While these were challenging times for Björn, reflecting back on that time, he takes pride in his ability to maintain a united front as parents and stay in the relationship:

I feel a sense of security maybe, that we both decided to act together. At the time I felt a big sense of disappointment and that it just wasn't working. It just doesn't work. Blah blah blah, then I thought that I would just leave. I never did though. I think it meant a lot that I never did. And when we talk about it, me and my wife, that's how I felt it was at the time. It's changed over time, it's a dynamic that has changed over time and I feel that it has meant a lot for Anton, and for everyone else of course, that we stayed together.

Björn states that it meant a lot to everyone that they stayed together throughout that trying time. He consciously chose to fulfill the role of the parent in order to maintain the family structure. By maintaining the roles of solid parents in a difficult time for the family, Björn reinforces the concept that roles matter. His role as an active father and husband brought him comfort and comfort to his family, even though he felt that it was not the easy choice to make at the time. His reinforcement of these roles tells us that the strain of the situation brought a form of role ambiguity between his relationship to his son and also his wife. In order to manage this ambiguity, he managed to alter the expectations of his role through upholding the role of father and husband (Hall, 1972).

Role ambiguity (Biddle, 1986) that forms between a family member with a serious mental illness forces caregivers into roles that may become a conflict to their established roles. Becka's father was diagnosed with schizophrenia and her mother, while not diagnosed with schizophrenia, suffered from a rare diagnosis called folie á deux. In this rare diagnosis, a partner can share in the delusions of the other person in the form of a shared psychosis (Kumar et al., 2005). Becka found herself in the unusual circumstance of caring for her parents while attempting to maintain the expectations and roles of the parent-child dynamic. In order for her to maintain these roles, Becka had to adapt to the situation:

And I turned into the person that was taking care of everyone else, making sure that I was that, you know, because, my younger sister was dealing with a lot of physical issues and some depression. And my younger sister, the way she dealt with things was that she would just internalize and escape. So she did a lot of like, you know, she escaped to like her fantasy novels and just didn't want to deal with it. And so for me, it felt like I had to be the one to keep the family together and strong.

Becka finds herself taking over the role of the parent for her younger sisters. While they were dealing with this situation in their own way, Becka felt that she needed to be the strong one in the family. Becka adapts to her parents' mental illness by becoming a parent towards her younger siblings. But this is simply the role directed towards her siblings and not toward her parents. What she feels is expected of her fractured into two parts with the onset of her parents' illness. *Role ambiguity*, according to Biddle (1986), is when the expectations placed on the role are unclear. In this case, Becka's role as daughter to her parents has an unclear demarcation from her role as sibling. Seeing the needs of her siblings lets her fill that role for her siblings while her parents struggle with psychoses. While acting more parental towards her siblings solves one problem, it creates another towards her parents. Becka now needs to resolve the ambiguous role of a daughter to parents living with a mental illness. She does this by overtly clarifying her role as the 'good daughter':

And so I, you know, was the one that saw the positive side. Extremely positive. A very positive person. But I looked for the good in every situation. And like, you know, and I just felt like I became kind of a parent in a way, because I had felt the need to give my sister some stability as well. [...] I felt like I needed to be a source of like, no, see, you did something good. And so like, I made sure that I didn't screw up at all and I wasn't, I couldn't afford to do anything wrong.

Becka maintains a fine balance between becoming a parent-figure to her younger sisters while also taking on the role of the good daughter in order to show her parents that they have done something good: they have been successful parents. While maintaining the role of the successful and positive child, Becka admits that she felt the need to separate her roles from her outer world:

So like there are a lot of self-protection mechanisms that helped me survive and thrive during everything that was going on. But now that I've come into like a safer place in my life, I those things started to like harm my connections. And so, like the compartmentalization of feelings was affecting my relationships. And it was before. But now is not a survival...like, I don't need it to survive.

The separation of her role in her family life from her work and social life ended up being a limitation after her parents passed away. The strategy that helped her maintain her day to day life while her parents were alive was catered to the expectations of the parent-child relationship and it helped Becka maintain a successful career and friendships by compartmentalizing the two worlds. Becka's ability to rigidly uphold her roles and separate the areas of her life came to fruition from the negative outcome of her parents' illness, which she then utilized to her advantage through resilient behavior (Van Breda, 2011).

Upholding roles can also be seen through performing traditional rituals associated with a certain role dynamic, such as father and son. Thomas and his son maintain a close relationship, and this is due to an arrangement they have made. It is important to Thomas to be able to monitor his son and he does this by fixing dinner for the two of them every evening. On first glance, this tactic would seemingly be employed by a parent concerned for a child that has newly moved out on his own. Yet this parent-child dynamic is upheld through a father who is in his nineties. Thomas and I discuss this evening ritual:

Thomas- Every day. Every day.

Allison- He lives here?

Thomas- No he has his own apartment in town, and we have an agreement that he comes here and eats.

Allison- Every day?

Thomas- Every day. I make food so it's a pretty good arrangement. People need structure.

This ritual allows Thomas to monitor his son through an established routine that is mutually beneficial. Upholding the role of caregiving father for Thomas has meant that he has been able

to manage his son's lifelong illness with a positive outlook, something that requires resilience (Zausniewski, Bekhet & Suresky, 2010). For many in Thomas' age, the son would be in the caregiving position and some could see this through the lens of resentment and the burdensome nature of this illness, but Thomas is an optimistic and proud father. He has even dedicated many years of his life to supporting other family members of those diagnosed with schizophrenia. By stabilizing the parent-child roles in the face of the upending nature of mental illness, Thomas has managed to strengthen his resilience and thrive in his role.

A summation of the findings of upholding roles shows the creative ways informal caregivers can adapt their behavior to best support their family member. By upholding the traditional and expected roles, caregivers can reduce role ambiguity that often goes hand in hand in relationships involving mental illness.

7.1.2 Recalibration

Through the course of data collection and analysis, a recurring theme of expectation management emerged in every participant to some degree. I refer to this as a recalibration of expectations toward the person with a serious mental illness. Recalibration is a strategy that allows for a person to alter the expectations placed on the caregiver as well as the family member. Through this, the caregiver is given more space to maneuver within his or her role and the expectations that they often entail. By subjecting oneself to the vulnerability of altered expectations and possibly negative outcomes (Van Breda, 2011), the caregiver is more thoroughly prepared to manage the difficulties that proceed from caring for a person with a serious mental illness in the long term instead of facing burnout more quickly. The resilient nature of this technique allows for caregivers to form their own understanding of what should be expected of their family members and even of themselves, instead of relying on standard societal norms.

Björn is a father to an adult son with schizophrenia. He is actively engaged in local and international support groups for family members of people diagnosed with schizophrenia. His son was diagnosed as a teenager and Björn describes how he and his wife have dealt with their son being diagnosed with a life-long disorder:

We said, ok this isn't so great. This is seriously sad. This isn't something you talk about casually. But I have a harder time with it than my wife. But we think that this is, this is incredibly hard, but it's not impossible to do something about this. There is no cure for it but there are ways to reduce the symptoms. And that's not terrible.

Björn is aware of the tragedy that this diagnosis can impose on a family, as well as the stigma associated with schizophrenia. He mentions that it isn't something people mention casually in conversations, which shows an understanding of the difficulty society has in comprehending what schizophrenia entails. Instead of dwelling on the negativity, he and his wife choose to focus on the positive aspects of being able to reduce symptoms in this diagnosis. There may be no cure, but there are ways to reduce the symptoms, as Björn says. What Björn has done here is a recalibration of a formidable challenge placed on a family.

Van Breda (2011) would refer to this as a resilient exercise that Björn is practicing. By recalibrating the situation, Björn makes it manageable in the long term. This adaptation of outlook (Masten, 2018) allows for growth and development within their family system which leads to further positive outcomes. Indeed, Björn continues to see the positivity within his relationship with his son. Björn recounts below how he interprets his son's admittedly sparse but relevant words of recognition for his parents:

He has said oh it's so nice that I have two parents that support me. He's said that. Not very often, but he has said it. And that has been a sort of reassurance that he has had a positive experience even if he has had very dark periods as well.

A parent of an adult son without a serious mental illness might interpret this passage as a minimal show of support by Björn's son. What Björn has done is reassess the expectations placed on his son and what a show of support should look like. For Björn's son, this show of gratitude is rare and therefore more meaningful for Björn. If Björn had more frequent expectations of gratitude from his son, he would most likely live in a state of constant disappointment. Instead, he and his wife choose to recalibrate expectations placed on their son in order to avoid this snare that many caregivers fall into (Szmukler et al, 1996).

Recalibrating expectations on a family member is a process that takes time and effort. Jackie has a son who was recently diagnosed with schizophrenia during his college years. She is also a primary caregiver to her husband who suffered a stroke eight years ago. Her son was recently

accepted to a teaching program out of state and her foremost fears are for her son's ability to manage stressful situations that other college graduates would be expected to handle:

I am very scared in the sense that I don't want him to get fired from a job or embarrassed if something were to happen. To where he would have delusional thoughts and couldn't stop them. I mean nothing is gonna happen like danger wise, but in the sense that he would be put on disability. Because he's at that threshold, he's not disabled, but he is diagnosed you know with a disability. So he's gonna run that fine line of trying to live a normal life with a very abnormal disease and functioning. So I'm very scared for his future to be honest, because I don't know. There's no telling with this disease, if it gets worse or if he can maintain it and get better, I just don't know. There's no answers and the doctor can't tell you either [...] like I say he's not as severe. He's pretty functioning so I don't know, I think with the other caretakers, if they are in full psychotic, you know they can't get them out to function and they are disabled at home would just be that much more extreme, to care for that.

Jackie's concerns for her son are not what most mothers are concerned with after their children graduate from college. Most mothers would be thrilled for a child being accepted to an elite training program for teaching. Jackie has lowered her expectations for her son considerably in order for her to temper her fears of the unexpected situations that could arise from her son being in a new stressful situation that is far from home. While lowering her expectations of his capabilities in stressful situations, she also manages to raise her expectations on her son by comparing his functioning to other caregiver/family member relationships that have more serious challenges, thereby allowing for him to be held to a higher level of capability to function within society without as much dependence as others in his situation. She has recalibrated expectations placed on her son as well as on herself in a caretaking role. Her experience as a caregiver altered her expectations of interactions with others and strengthened her understanding of what is expected of a caregiver which she describes as follows:

Because I've had a lot of things...serious things that have happened, I couldn't imagine a parent that, you know their life has been so smooth and this is the first huge blow. I've had a few blows in my life, so it didn't change me as much as it could have. In the sense of the shock and the reality that life is just not a bowl of cherries. But um, what changed me is that I think I got bolder, and more self-reliant. I really don't need to prove as much to people. Like, of course I don't share this with people that I don't trust but in the same sense, I feel like I'm a little bit harder in my aspect of what's important and what's not. I think it's strengthened me in that sense, but it's also made me a little bit sadder about the world.

Jackie has managed to recalibrate her expectations of how a caregiver should act and also lowered expectations on others she comes into contact within her role as caregiver. By reinforcing her role as caregiver, Jackie can more clearly and accurately assess the expectations placed on her as well as how much expectations she can place on others. In other words, she not only learned to cope with this strain, but she actually gained strength through upholding her role as caregiver. This what Van Breda (2010) defines as resilience, thriving in the face of negative outcomes.

Recalibration allows for an increased capacity to care for someone with a long-term illness. The above findings show a systematic management of expectations that encourages seeking out the positive in the face of negative outcomes.

7.1.3 Differentiating the person from the illness

A frequent strategy used by the participants that this study has revealed is to differentiate the symptoms of these diagnoses from the family member. In this section, I discuss how separating the role of the family member from the role of the mental illness protects the caregiver from repeated burnout. This is not something that can be done by someone unfamiliar with the individual as symptoms of schizophrenia or bipolar disorder often manifest in a unique fashion according to each person (Correll & Schooler, 2020). When a caregiver is able to differentiate these symptoms from the behavior of the family member, the caregiver is given an opportunity to protect and maintain the relationship.

Sandra's daughter was recently diagnosed with schizophrenia in her thirties. Due to the abrupt diagnosis that caught Sandra off guard, she had difficulty understanding the difference between her daughter's symptoms and her daughter's behavior that was damaging to their relationship. The frustration caused by not fully being able to separate the two leads to tension between the role of caregiver and the person receiving care. Sandra describes what it felt like to learn how to separate the diagnosis from the person after taking a course for family members of mental illness through the organization NAMI and how it affected her relationship:

I was taught to do that during the NAMI classes. Before I did their 12-week course on mental illness, I was offended at her behavior. I only saw a snippy, rude, irresponsible person where there used to be a nice, caring, capable adult. She went from a nice, caring, capable adult to like

a 14 year-old with a chip on their shoulder. You know, um, and I could not separate the illness from my daughter because I didn't know it was an illness. I didn't believe that mental illness was an illness and you made choices whether to be good or bad. I didn't know that some people's judgment would just evaporate. I didn't believe schizophrenia and bipolar disorder were real diseases.

The perspective shifted for Sandra. After learning to separate the behaviors associated with schizophrenia from the behaviors of her daughter, Sandra was able to protect the roles of mother and daughter. Sandra's description of being overwhelmed by her daughter's behavior is what Biddle (1986) refers to as *role overload*, meaning the expectations of her role as mother became too great. By differentiating her daughter's illness from her daughter, she is able to reduce the expectations placed on her in a caregiving capacity. Sandra illustrates an effective strategy of reducing the mental burden of caregiving by unloading the symptoms of the diagnosis off her own shoulders and placing it directly on to the illness. Caregivers are in a singular position to be able to differentiate the qualities associated with the person and the behaviors manifested from mental illness. For formal caregivers, this familiarity with the patient is most likely never fully developed.

Learning to differentiate the person from the illness is something that can take time, especially in situations where caregivers meet persons with mental illness as an adult. Kent was married for many years to a woman with bipolar disorder and he recounts the first time he met her when she was in what he refers to as a slump and later, when she was in a manic phase:

The first time I saw her, when he introduced her, she looked like a little gray mouse, just a little tiny gray mouse. I should have brought pictures, but I didn't want to reveal too much maybe. But you would have seen the difference. It was just an enormous difference, when they are down in a slump and up at the top. It's not the same person as the person I met in the beginning.

What Kent recounts is a difference so pronounced in his wife's manic versus depressive states that he sees a physical difference between the two. As a family member, Kent is describing an enormous difference between the two personalities. Mental healthcare workers often come into contact with people diagnosed with bipolar disorder while they are at one extreme or the other. There is rarely the amount of long-term contact that allows for formal caregivers to witness both states. Kent later recalled how the pattern in his wife became predictable and he could recognize her different states, making it more manageable to adjust to how to best manage each

situation. Even the unpredictability of bipolar disorder developed its own pattern for an informal caregiver such as Kent. By learning to recognize the illness, he could better cope with his wife.

While differentiating can be a helpful strategy for some, it can also create challenges for others by clashing with a person's idea of his or her family member's identity. A common occurrence between family members and caregivers is the complicated nature of medicating a person with a serious mental illness. Many experience a change in personality of a family member after medication. After many attempts to encourage her father to seek professional help for his schizophrenia diagnosis, Becka described changes to her father that she experienced as an alteration to the essence of who her father was:

And he just wasn't able to really focus like his sense of humor was still there. But it was like disconnected. He was just a shell, you know. And my dad would, you know. And I like, maybe I hate the medication more because before he's on medication, yeah, I'd have to deal with paranoia. But then when the paranoia wasn't there, he was just always on and very engaging and made everyone laugh regardless of who they were. Always making people laugh, making tons of food, dancing like goofing off like he was just such an energetic, dynamic, present person. And so to become that, it was just like this huge shift.

Where a formal caregiver would see the success of reduced symptoms of paranoia, Becka considered the medication to be a failing on the part of his doctors. Instead of clearly being able to differentiate the illness from the person, the medication, according to Becka, blurred the personality of her father and she could no longer easily discern the paranoid thoughts from his effervescent personality as she could before he was on medication. Before he went on medication, Becka became adept at differentiating the ill person from her father. The strategies she implemented earlier had worked for her. After medication, she struggled with the consequences that medication can have on patients, which can sometimes be experienced by caregivers as a loss of personality. The roles that Becka had developed to manage her relationship with her parents no longer worked to the benefit of their dynamic. For Becka, not being able to differentiate the person from the illness any longer due to medication created role ambiguity (Biddle, 1986).

7.1.4 Playing along

The material revealed a distinctive strategy that is specific to informal caregivers. I call this strategy ‘playing along’, or in other words, indulging a family member’s reality temporarily in order to encourage positive outcomes. Caregivers are in a singular position to utilize this strategy because they are familiar with the family member’s specific patterns of psychosis and caregivers that are also family members are not bound by formal or professional codes of ethics such as mental health workers or doctors are. This section aims to illustrate how caregivers use this strategy to benefit both parts in the relationship.

A common symptom of schizophrenia is to withdraw into oneself and isolate with one’s own thoughts and ruminations (Cullberg, Skott & Strålin, 2020). It can be challenging to break this negative behavior without some form of intervention. What makes schizophrenia and bipolar disorder especially challenging is the lack of insight of the person with the diagnosis on the state of his or her own mental state. Delusions are as real to the family member as anyone else’s experience of reality. Unfortunately, this can lead to complications in convincing a family member to seek treatment when necessary. Sandra explains the difficulties of communicating with her daughter while she is in a psychotic state:

When she was totally psychotic, she would stay up 24/7, screaming to invisible people that she thought watched over the city and she thought only she could hear. She thought it was a gift, she wasn’t hallucinating, she was talking to spiritual beings. She will never tell you she was hallucinating. She will never, she thinks they’re gone now. And if you’ve ever talked to someone with a delusion, you cannot talk them out of their delusion, it’s impossible.

The impossibility of convincing her daughter that her delusions were not real are a common description of the frustrations of living with a person with a serious mental illness (Correll & Schooler, 2020). Instead of trying to convince this person that their reality does not exist, this study has observed a pattern of caregivers playing along with their family member’s reality in order to achieve better state of care. An example of this is Thomas and his son. Thomas used the strategy of playing along in order to help his son break out of his bubble:

But when he was holed up in his bubble, I took advantage of the ‘helpless method’ in this way that I just sat myself down in front of the computer and then I purposely crashed the computer so the computer would show ERROR. You know in the 80’s, computers weren’t what they are

today and so I would leave the office and holler after Niklas. Niklas! The computer is screwed up again, can you help me? Yeah yeah, I'll be in in a minute, he would say. And then he would look at the computer and then look at me and say, you're hopeless, I helped you with this last week! And I would say yeah I know I'm just not good at this. And then he would sit down and help me fix the computer. So you develop strategies.

Thomas found a method of helping Niklas break out of his bubble by using something that Niklas enjoyed and excelled at by pretending to be helpless. This served two purposes; Niklas broke out of his bubble of isolation and he got to use the opportunity to practice something he showed talent and interest for, which is the part of Niklas that his father was interested in bringing forth. Thomas was able to redefine his role as purely caregiver and encourage a relationship that was seemingly more balanced. This mirrors what more 'normal' adult parent relationships appear to be as the parent grows older and struggles with new technology. Thomas was able to provide that normalcy for Niklas and thus, reinforcing the familiar roles of father and son (Masten, 2018). By playing the helpless parent, Thomas offered an opportunity of escape from his son's isolating thoughts.

Becka has also used the playing along strategy with her parents in order to convince them to settle down in one spot instead of moving from town to town to avoid 'the bad guys', as the delusion was referred to. Becka's parents believed that there were people trying to harm their family and they moved frequently in order to prevent their family from coming to harm. Becka outlines her process and how she finally ended up in a position to play along with their delusions:

Yeah, I did it the wrong way for a really long time. So I was that kid who couldn't understand why my parents were saying these things. And so, they were so absorbed with like even you don't believe us. You don't believe us. You have to believe us, you know. And I would tell him, well, it's, it's, this doesn't make sense. Think about it like I try to reason with them as if they're real, you know, because I didn't really understand because I was so young that like their reality was as much their reality as my reality was mine. And so, like, I tried to convince them that reality was not real life. And that's not, that wasn't helping because then they just felt like I wasn't on their side. And so we still would talk, you know, almost every day. And but a lot of it was like the first part of it was just argue with them. [...] And then finally I would change tactics sometimes and say, well, you know, the bad guys are taking so much like can you just like have conversations with me? That would finally like click them over. We could talk about normal stuff. I love you. Everything's great. Start again the next day.

Becka ran the risk of losing trust and contact with her parents entirely due to her arguing with them about what is real and what is not. In the end, she discovered it was smarter to use their delusions to her advantage by admitting that they exist but convincing her parents not to let them take up all of their energy. This is what Masten (2018) refers to as promotive and protective processes. A protective process is a skill that encourages resilient behavior such as problem-solving skills. Becka has been able to solve this problem of not being able to break through to her parents reality by side stepping their reality in order to accomplish her goal of maintaining communication and trust with them.

The strategy of playing along allows these informal caregivers access to motivational techniques that are normally out of reach for formal caregivers. Instead of arguing about which reality is real, it is a way to cut through to the true objective of informal caregivers, which is the best possible care for their family members.

7.2 Family caregivers: descriptions of their role in relation to formal support systems

Informal caregivers have limited, if any, power in executing formal care for their family members with a serious mental illness. Mental healthcare has moved away from the former practice of institutionalization (Cullberg, Skott & Strålin, 2020) which is rare and often only during states of serious psychosis. Instead, it has moved towards medication, therapy, and living as independently as possible (ibid.). In order for this to be accomplished, there is often an informal caregiver providing support and structure. An informal caregiver may most likely know the person with a mental illness's symptoms of recurring psychosis better than a psychiatrist. This study has shown that caregivers take on different roles in the face of formal support systems in order to ensure proper care of their family members. The three main roles that emerged from the data suggest three commonly occurring roles. The first role is what I refer to as the *role of the expert*. The role of the expert signifies a distinction of the caregiver as the expert of this person and the person's symptoms of the illness. The second role is what I have termed the *role of identity guardian*. An identity guardian's role is to delineate between what this person's true identity may be in the face of medication or treatment which may lead to changes in personality. The identity guardian aims to protect his or her family member's true identity. The last role is what I refer to as the *role of the ally*. The ally forms an alliance with formal caregivers in order to benefit the family member cooperating, but this can be at the

expense of trust built up between the informal caregiver and family member with a diagnosis. The following section provides cases where the participants of this study partook in one or more of these roles in order to achieve a successful outcome for their family members.

7.2.1 The role of expert

Throughout the interviews, a reoccurring pattern of informal caregivers emerged that expresses an amount of expert knowledge of the family member with a serious mental illness. This expert knowledge is specific to the person and would be difficult for formal caregivers to recognize. This expertise is gained through repetition, trial and error, and experience with this person, not the illness specifically. Many people with a serious mental illness experience psychosis, but every patient experiences it in a different way. For some such as Jackie, talk of religion can be a sign of an oncoming psychotic episode. For others such as Sandra, it has to do with her daughter talking to herself more frequently. How they learn to manage these events puts them in the role of an expert.

Thomas was devastated after having to check his son into a facility when his psychosis got to be too much for the family to handle. The stress of this situation was compounded by the fact that his son resented his decision and did not want Thomas to visit him. In order to win back his trust, he used a clever tactic:

It hurt. So I looked a little curious. Yeah, it was you that destroyed my life, he said to me. His mom and big sister got to come and visit him. He was checked into that facility for three months I think. Then he came to a closer facility and we visited him every day. He still didn't want anything to do with me, but he was still seeing everyone else in the family. I discovered that he really likes cookies. So we sat down in the cafeteria at the hospital and I brought coffee and cookies and juice. Then I got to sit at the same table as him.

Thomas combined his useful knowledge with persistence and found success through this method. Resilience can be seen in this example by continuing to make an effort where most would justifiably be overwhelmed (Szmukler, et al, 1996). What could be seen as a small gesture of kindness ended up opening the lines of communication that had been damaged through the process of institutionalization against his son's will. This had been so damaging to their relationship that Thomas decided that this was the only regret he had through the whole

process of caring for his son over the course of fifty years. After this point, Thomas focused on building trust by using methods that relied on his son as a full participant in his own care. In order to do this, he relied on ways to manage the dark periods with his son through talking and catering conversations to what his son was most interested in:

And then we began to talk about how much he meant, that I knew...so he said I am not born on this earth so I don't have a right to these resources. That was one of the delusions he had. That was the start of roughly a half a year's worth of nightly talks. We talked every night. When I came home at around one in the morning and he sat up and waited for me [...] I also had a strategy with this. We would just pass out. And we did alright. [...] I passed out around three or four every night and then I would get up again, but that's the way I handled it. It might have been irresponsible really. I maybe should have let his doctors know. He is a suicide risk, bring him in. But I knew if I did that, he would be medicated to the point where he would be unrecognizable. So I did it this way instead.

Thomas admits that it might have been wiser to involve formal caregivers in this case but his assessment at the time maintained that this was the best choice for his son. By taking on the role of expert in the care of his son, he found strategies that involved caring for him that did not have to require forced treatment or medication. The role of expert that Thomas manifests in this example is in relation to formal healthcare systems. By doing this, Thomas is saying that he knows his son better than the doctors and nurses. Past experience with the healthcare system has taught Thomas that he is more of an expert on his son than professionals. Put plainly, Thomas became an expert only after the formal healthcare system was found lacking. Biddle (1986) would describe this role development as arising from role ambiguity. In the face of inadequate care from a formal system which led to an ambiguous definition of who is, in fact, in charge of his son, Thomas filled the role of the expert.

Sandra stepped into the role of expert when she repeatedly struggled with formal healthcare systems and care for her daughter. Sandra's daughter developed schizophrenia as an adult which led to a confusing period for Sandra. Her daughter Emily was resistant to taking medication and repeatedly ended up with negative symptoms such as isolation and auditory delusions (Černis, Freeman & Ehlers, 2020). Sandra had to learn how to manage the everyday care of her daughter, even when she seemed unresponsive for long periods of time. The following passage is a description of how Sandra coaxed her daughter out of isolation:

Knock knock knock hi Emily are you there? What mom? Ok just wanted to know if you were in there. After a week or two of that, and this is during psychosis, she would stop talking to her people and say, oh my mom's at the door hold on a minute I gotta talk to my mom. And she's talking out loud and she doesn't think I can hear her. And I would say hi Emily it's your mom, I know it's you. Do you want dinner? No I'm not hungry. After a while she would open the door and take food from me. So it took like two weeks to get her to talk to me, then it took like two weeks to take dinner every night at six, then the next thing I added in is do you wanna take a walk with the dogs? No no no, finally she said yes yes yes. Now it's four years later and I still knock on her door and tell her it's time for dinner and after dinner we go to walk the dogs. Now we have a new routine which is watching television after we walk the dogs. And those things were all established while she was psychotic and now every night with me, even stable on the medicine.

What Sandra has done here is create a consistent form of care for her daughter that did not involve formal treatment. She slowly incorporated new levels of routine that consistently encouraged more socialization and a sense of normalcy. Sandra has repeatedly mentioned the difficulties she has had dealing with mental healthcare workers. The systems in place make it strenuous on informal caregivers to be able to input their expert knowledge they have developed. Sandra becomes the expert on establishing healthy routines for her daughter which allows for her to minimize the risk of her daughter needing hospitalization. Masten's (2018) concept of promotive and practices is shown through Sandra's use of skills that develop over time, making her a more resilient caregiver in the process.

The results of this study show that caregivers take on a role of expert in order to best suit their family member, but also to reduce unnecessary contact with formal healthcare services. An informal caregiver becomes accustomed to the behaviors and symptoms displayed by his or her family member, this can be used to the benefit of the informal caregiver in the long-term.

7.2.2 The role of identity guardian

While being an expert on a person's behavior takes time and careful observation, understanding someone's identity can be an entirely different matter. Identity to many caregivers does not describe the behaviors related to the diagnosis, instead it has to do with the person's essential nature. This section aims to acknowledge this distinction by demonstrating how caregivers

involved in this study have involved themselves in efforts to protect what they believe to be the true identity of their family members.

For some caregivers in this study, the interaction between a family member and formal healthcare systems led to taking on the role of an identity guardian. Becka's father decided to seek treatment after many years of encouragement. He was put on anti-psychotic medication in order to manage his delusions. Becka recalls her first encounter with her father after he had received medication:

And so to see this person, he was so full of life and so interested in like being around people and making people feel good who are around him and all that stuff so to see this like, shell that like, you know, I just I couldn't. It was, really I hated it. I hated it cause I didn't even recognize my dad really. And that, you know, and I knew it was him, but it wasn't him. And so I I just didn't want to, I didn't want to face it at that point. You know, it's just like, this isn't my dad.

What Becka describes here is an alteration of who her father had been to her previously. She did not feel that her father on medication was the same person as he once was. While this might make sense to many caregivers with a long history with their family members, this is not necessarily the case with formal caregivers. As a formal caregiver, this situation might induce a response of encouragement due to the reduction of paranoid delusions, which is often times the only measure a formal mental health caregiver can give. There is no formal checklist for maintaining an identity unbeknownst to staff at a medical facility. For many informal caregivers, this is a challenge that they may exclusively recognize. Becka was aware that medication could reduce his paranoia and delusions but for her, it was not worth the loss of his identity. Becka took on a protective role of his identity in the face of formal treatment through medication.

Some of the caregivers took on the role of identity guardian by challenging the routines and methods of formal caregivers. An example of this is Thomas while his son was in an inpatient facility. There were rules about what was allowed in the patients' personal rooms. Thomas knew that his son was interested in computers, so when the staff informed them that computers were not allowed, he resisted this decision:

He was very sad that he couldn't have his computer in his room. So I said you guys are so talented and you have taught us so much about how you work and all that and you have taught

us that you should always start from the healthy side. The healthy side of a person. From there you can work your way forward. You are so right, the facility director told me. Then I told him that his computer skills are a part of his healthy side. His logic is his healthy side. Emotions? Difficult. So in the end he got to have his computer.

The rules at that facility were no doubt put in place to encourage socializing and discourage isolation. Thomas recognized this decision but challenged it in order to protect his son's identity, or what he refers to as his healthy side. Thomas confronts the formal methods of treatment in order to preserve the healthy part of his son which is what Thomas believes to be part of his essential core. The roles that Merton describes with his role-set theory (1957) are used to accomplish a goal. But playing a role also implies that there are times when we as individuals are not playing a role. This is what Irving Goffman (1956) refers to as being 'backstage'. Informal caregivers have an intimate knowledge of the person's backstage persona, or what they might believe to be the person's true identity. Formal caregivers in this example have missed how tools related to Thomas' son's identity can benefit his treatment.

The role of identity guardian provides informal caregivers a chance to preserve what they believe to be the most essential qualities of their family members. Mental illness may already be debilitating to a person's personality. The intervention on behalf of formal caregivers can at times worsen these personality changes. Informal caregivers use the role of identity guardian to protect the integrity of the family member below the surface of the mental illness.

7.2.3 The role of ally

The role of the ally is what this study refers to as a strategy used by informal caregivers toward formal healthcare systems in order to achieve a specific goal. The goal is often to improve the care of a family member amidst the obstacles that formal healthcare systems have in place for informal caregivers. This study has shown that this role of ally is taken on in situations where there is an imbalance of power within the dynamic of informal caregiver, formal caregiver, and patient. The informal caregiver is then in a position to align with formal caregivers in order to achieve his or her goal. The following examples illustrate how the role of ally takes shape with informal caregivers.

Having a family member in a psychiatric care facility is often experienced as a very stressful situation for informal caregivers. Because of privacy laws in both Sweden and the U.S., information relating to the patient is confidential unless permission is explicitly granted. This puts informal caregivers in a vulnerable position, as formal caregivers have often reported feelings of frustration and annoyance with relatives in this position (Hjärtlag et al., 2017). Jackie's son was taken to a psychiatric facility for treatment of a psychotic episode. Jackie feared for the quality of care for her son in a facility where she had limited contact. Jackie's strategy to ensure better care for her son was to become an ally to the nursing staff:

I just wanted to know what I needed to do from them. Because they are the experts and I was like what, so I was trying to feed off of them or make friends with them, so I would call the nurses at the hospital and I was kind to them so they would number one be kind to my son, you know because I don't know what's happening in the hospital. And then so that they would be kind to me as well. And it did work, because they were kind. But yeah I don't feel, I didn't have to scream or anything like that. Because I was just in such a vulnerable spot for my son's care that I didn't dare.

Jackie was very aware of her vulnerable position in relation to formal caregivers and she was also aware of how relatives can be perceived by staff. In order to minimize the risks of staff possibly taking out their frustration with her on her son, she formed an alliance with the staff in hopes that they would, in turn, treat her son kindly. Jackie's assessment of the situation was that it was a successful tactic. As previous studies have found, relatives of people diagnosed with schizophrenia often experience negative interactions with mental healthcare workers (Weimand, 2012). Affiliated stigma of relatives of people with a serious mental illness (Zhang et al, 2018) lead caregivers such as Jackie to find creative strategies to receive proper care without being seen as bothersome. For Jackie, the role of the ally allowed for a way around these challenges. Not only did she see this as a strategy to help her son's recovery, she formed a genuine contact with one of the nurses who had lived through a similar situation. Jackie did not just cope with this situation, she adapted successfully to a system that normally does not work in her favor (Masten, 2018).

Some informal caregivers use the role of the ally alongside their family members as in Jackie's case, and others use the role of ally against the wishes of their family members, such as in the case of Sandra. The use of the role of ally is a strategic one, meaning there is a desired outcome from these actions. For Sandra, her goal was to get her daughter to go on medications against

her daughter's wishes. In order to accomplish this, Sandra needed to align herself with the goals of formal systems, which in this case happened to be a judge before a court hearing. Sandra's daughter had been arrested again for her erratic behavior due to a psychotic episode. The U.S. judicial system handles a large portion of the mental health community (Roberts, 2019) and Sandra was at the behest of the judge presiding over her daughter's case. The judge has the power to send her to jail or to require her to receive court ordered care. In the following quote, Sandra pleads with the judge to go against her daughter's wishes and order her to take her prescribed anti-psychotic medication:

I went to court the next morning and asked to speak to the judge which is very unusual. The sheriff told the judge that I was there. The judge asked who I was and I said I'm her mother. Emily luckily enough, started screaming at the judge that that's not her mother. That's not my mother! And he looked at me and said who are you and I said I'm her mother and Emily started screaming again That's Not My Mother! My mother would never blah blah blah! And he looked at me again and said does she live with you and I said yes. I said, she talks to people up there, I pointed at the sky, and then I looked at him and said and she can read your mind. He looked at me and knew instantly in that one sentence that my daughter was kooky, right, and he said what help does she need and I just said medication. I just said one word, medication. He looked at Emily and she was still going off, blah blah blah! And uh, he said young lady shut up! I'm considering letting you out of jail and you need to be quiet and listen. And he said to her finally when she quieted down, he said will you take medicine? Because I'll let you out of jail if you take medicine. And she started screaming at him some nonsense and he said will you take your medicine? I'm letting you out of jail if you'll take medicine.

The interaction between Sandra and the judge went from affirming if her daughter knew who she was to a potentially life changing decision for her to take medication, and all of this happened in a very short amount of time with limited interaction. Sandra reflects on this moment as altering the path of her daughter's wellness. These decisions were made on the basis of Sandra taking on the role of the ally with the judge. She needed the backing of a formal system in order to compel her daughter to medicate, which in the capacity of an informal caregiver, Sandra has no ability to do. This alliance was beneficial to both informal and formal caregivers. The role of ally is a complex one. There are situations such as this where an informal caregiver finds oneself in a position that opposes the will of the family member in question. Sandra understood in this case that her daughter would not respond to a more subtle tactic such as playing along. Sandra was concerned for the safety and well-being of her daughter after multiple arrests and encounters with law enforcement. Medication can be a dividing issue

amongst caregivers, but Sandra acted out of what she believed to be the best interest of her daughter. The role of ally allowed for this intervention measure to be put into place within a system that severely limits the powers and influence of informal caregivers.

The role of ally displays itself through these examples. There are times when informal caregivers' judgment leads them to form an alliance with formal caregivers in order to benefit family members. There is a delicate balance of trust and loyalty to the family member and an obligation to the larger picture of concern for the well-being the family member's health and the health of others. If the risk of self-harm or harm to others overpowers the risk of breaking trust, informal caregivers are in a precarious position to make critical judgment calls, often with limited support from formal caregivers. The role of ally therefore emerges most often in times of serious concern.

8. Concluding discussion

8.1 Summary of findings

This study has shown that there are various strategies used by informal caregivers of people diagnosed with a serious mental illness. These strategies entail taking on a tactical role in order to manage the dynamic between either informal caregiver + family member, or informal caregiver + formal caregiver. The strategies identified in this study have been used to either manage a family member with a serious mental illness or to manage the care given by mental healthcare systems. In both cases, these informal caregivers have found artful ways of maneuvering around formal systems of care on one side and diagnoses that challenge the self-awareness of a person on the other. Both require informal caregivers of people with a serious mental illness to shift into different roles at different times in order to best cope with the situation they have been presented with.

This study has identified four different types of caregiver strategies used to manage family members with a mental illness. The first strategy, which I refer to as *upholding roles*, allows for caregivers to resolve the role conflict that arises from caring for a family member outside of the traditional mold. A child caring for her parent may feel the need to reinforce the role of daughter in order to maintain a sense of normalcy. A parent caring for a child with a serious mental illness may feel the need to uphold the traditional roles of parent/spouse to provide clear expectations on oneself and others. The second strategy, *recalibration*, is used to re-evaluate the established expectations placed on different roles and adjust in order to cope in the long term. This could mean that a parent lowers expectations placed on a child or shifts the expectations to match what is within reason for the circumstances at hand. The third strategy, *differentiating the illness from the person*, is a tactic that separates the family member into two parts. One side is the illness and symptoms, another side is the true identity of this person. By separating the symptoms from the person, caregivers learn to ration their energy to what types of behavior is worth addressing and what is not. The strategy of *playing along* is a singular strategy used by informal caregivers that allows for a level of indulgence into the reality of a

psychosis in order to nudge family members towards treatment. This strategy is not suitable for formal caregivers as it would be considered unprofessional.

This study has also identified three roles taken on by informal caregivers towards formal healthcare systems. The first of these roles is to become the *expert*, meaning the person who has expert knowledge on the person with mental illness. By becoming the expert, the caregiver is in a position to benefit the care of his or her family member through observation and experience. The second role that informal caregivers take on is the role of *identity guardian*. An identity guardian aims to maintain the integrity of the family member through the process of treatment and medication, which through a formal caregiving perspective is most concerned with reducing the symptoms of the illness and not necessarily the full well-being of the patient. The last role identified is the role of the *ally*. The ally is interested in promoting what he or she believes to be the best care possible for the family member through strategic alignment with formal caregivers, even if that means going against the wishes of the family member.

8.2 Progress through resilience

The unforeseen result of this study was that informal caregivers do not just find ways to cope with the burdens of caregiving for someone with a mental illness, they thrive in the long term. This is a result of what I refer to as the *resilience progression*. These caregivers have shown a process of trial and error through learning. The strategies identified in this study suggest a pattern of resilience exercises that encourage progress, much like how children exposed to smaller amounts of stress also gain resilience. The strategies are implemented in order to manage the two-front offensive that is caregiving for a family member with a serious mental illness has led to a form of adaptation that allows for growth and strength where it is expected of these caregivers to experience burnout. This progression of resilience is uncommon amongst long-term informal caregivers of other forms of illness such as dementia and cancer (Almberg, Grafström & Winblad, 1997; Papastavrou, Charalambous & Tsangari, 2012). The underlying difference between these illnesses is that there is no cure for mental illness, only management, which can show signs of improvement or signs of degradation throughout a lifetime. Illnesses such as cancer and dementia have a line of progression that leads in a unilateral direction with less fluctuation. The caregivers in this study have managed to progress and adapt to caring for a family member for the long term. The skills learned through taking on different roles in

opportune situations such as playing along, upholding roles, differentiating the illness from the person, taking on the role of the ally, expert, or identity guardian; all of these have allowed for these caregivers to achieve a progression of resilience in the face of hardship.

The relevance of these findings is of particular interest to research fields within social work. As a profession, social work's mission is to care for people in need. Informal caregivers of people with a serious mental illness are not only an often overseen group in need of support, they also provide unique strategies that social workers can benefit from. It is unfortunately more common for informal caregivers to be disregarded by formal caregivers. The strategies and roles found in this study suggest that there is a misjudgment on the part of formal caregivers of what motivates informal caregivers to intervene on behalf of their family members. These strategies of managing an unpredictable illness provide constructive and receptive approaches to care that rely on ingenuity, imagination, and a perceptive understanding to what the person behind the diagnosis needs to thrive. We have an obligation to care for the most vulnerable in our community, including those who care for people living with a serious mental illness. It is therefore beneficial to begin prioritizing informal caregivers by offering equally imaginative and perceptive care to them as they provide have provided for their family members.

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10. Appendix A

Interview Guide

Background

1. What kind of relationship do you have with the person affected by schizophrenia?
2. How much contact do you have with this person?
3. What is his/her current mental health state?
4. How has schizophrenia affected your relationship to this person?

Symptoms

1. What are some initial signs or symptoms that concern/have concerned you of an upcoming psychosis/paranoia?
2. How many people are aware of these signs?
3. Do you/did you feel comfortable addressing these concerns to your loved one?
4. Have you experienced negative consequences from addressing concerns in the past to your loved one?
5. How much responsibility do you feel for keeping track of these symptoms?

Strategies

1. Can you describe a strategy that has had positive outcomes?
 2. Can you describe a strategy that has had negative outcomes?
 3. What form/forms of intervention have you attempted to carry through?
 4. What are your biggest concerns during stressful periods?
 5. What was your biggest concern in terms of your relationship?
 6. What has been your experience with mental health professionals/social workers?
 7. Have you felt that they have listened to you?
-
1. How do you feel that this experience with your loved one has changed you?
 2. How would you describe the expectations placed on relatives?
 3. Do you feel there are any special skills you have developed through this experience?
 4. Do you schizophrenia as separate from the identity of your loved one?

5. What are your thoughts on medication?