Exploring the Experiences of Parent Caregivers in Schizophrenia

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Abstract

Purpose

Family caregiving is vital to the health of persons with schizophrenia and without this support, many individuals would struggle to maintain their community tenure. While there is an abundance of literature that explores family caregiving in mental illness generally, less is known about the experiences of family caregivers of persons with schizophrenia. Furthermore, the primary caregiver for a person with schizophrenia tends to be a parent, and parent caregivers' experiences differ from those of other types of family caregivers, such as spouses and children. Often, the experiences of parents' caregiving for a person with schizophrenia are intermixed with the experiences of other types of family caregivers, which might minimize or distort their particular subjective realities. The purpose of this Thesis is to explore the experiences of parent caregivers of adult children with schizophrenia (ACWS) through a synthesis of existing literature and interviews with parent caregivers.

Objectives

There were two objectives: 1) to review existing literature on the experiences of parent caregivers of adult children with schizophrenia and 2) to explore the experiences of parent caregivers of adult children with schizophrenia in a large urban Canadian city.

Methods

This was a two-phase study using an emergent design. Phase one was an evidence synthesis of qualitative research on the experiences of parent caregivers of adult children with schizophrenia, modeled on the Joanna Briggs Methodology for qualitative systematic reviews. The review was conducted in accordance with the ENTREQ statement and all standard procedures were followed for citation screening, data extraction, and quality appraisal. Five studies were included from four countries (2009 – 2016). Phase two was an Interpretive Description qualitative study using interviews to explore parent experiences of caring for adult children with schizophrenia. Twelve parents (eight mothers and four fathers) completed interviews. In both phases of research, conventional content analysis was used to analyze data.

Findings

Findings from the qualitative evidence synthesis revealed that parent caregivers of ACWS experience psychological distress, losses related to self and to child, and significant consequences for their families. Importantly, parent caregivers frame their experiences in positive and meaningful ways, which help them cope with their role. Parent caregivers included in the qualitative study described experiences of uncertainty and change related to their child's schizophrenia and subsequently the actions they needed to take that were counter to their expected parent role. These parents further described the negative and positive effects of caregiving on their own lives. Finally, when comparing the findings of both phases of research, there were two cross-cutting considerations. First, parents have difficulty using and understanding the resources available in the mental health care system. Second, parents experience distress in their caregiver roles, and this distress is often induced or worsened as a result of barriers to treatment for their ACWS.

Conclusion

Parent caregivers for persons with schizophrenia experience tremendous difficulty navigating the health care system. These challenges compound the psychological distress they already experience, by virtue of their role. Often, these parents prioritize their caregiving responsibilities above their own health and well-being. Health care providers must understand, acknowledge, and address parent caregivers' needs, advocate for a less fragmented mental health care system, and support parent caregivers to be empowered and satisfied in their role.

Co-Authorship

1. Amanda Vandyk RN, PhD, Assistant Professor, School of Nursing, Faculty of Health Sciences, University of Ottawa

As my thesis supervisor, Dr. Amanda Vandyk co-authored each manuscript and provided guidance on the overall thesis design including conceptualization of the two studies. Amanda provided a substantial contribution to the overall writing and development of the final document.

2. Jean-Daniel Jacob RN, PhD, Associate Professor, School of Nursing, Faculty of Health Sciences, University of Ottawa

As a member of my thesis committee, Dr. Jean-Daniel Jacob co-authored each manuscript, assisted in conceptualizing the qualitative study, and provided guidance on the overall thesis design

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As a member of my thesis committee, Dr. Christine McPherson co-authored each manuscript, assisted in conceptuali zing the qualitative study, and provided guidance on the overall thesis design.

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As a member of my thesis committee, Lisa Murata provided content expertise and guidance on the overall thesis design. Lisa co-authored each manuscript with a particular contribution to the qualitative evidence synthesis (QES). As second reviewer for the QES, Lisa screened all articles retrieved from the primary search, assisted with data extraction of final articles, and reviewed the quality of included studies.

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Chapter Three, Exploring the Experiences of Parent Caregivers in Schizophrenia: A Qualitative Evidence Synthesis

Chapter One

Introduction

Introduction

Family caregivers play an integral role in the management of chronic illness. The average family caregiver will provide approximately 24 hours of care per week, for a period of four years, when they are supporting a family member with a physical illness (National Alliance for Caregiving, 2016). Additional responsibilities are typical when the care recipient has a mental illness, with these caregivers providing care for an average of 32 hours per week, for a period of nine years (National Alliance for Caregiving, 2016). Not only is there a weekly increase in the time spent in the caregiver role, the family member assumes this role for much longer.

The importance of family caregivers for persons with mental illness is receiving widespread attention. The Mental Health Commission of Canada (MHCC; 2012), for example, has put forth several recommendations that specifically address these family caregivers, recognizing that their perspectives and well-being are priorities. According to the Mental Health Strategy (MHCC, 2012), family caregivers need support to foster recovery and well-being and provide care for their loved one. In addition, these caregivers require access to respite services, financial aid, and support in the workplace (MacCourt, Family Caregivers Advisory Committee, & Mental Health Commission of Canada, 2013). While family caregiving in the context of mental illness is not a new area of study, national agendas are widening to recognize the impact of mental illness beyond the individual level, and specific recommendations are needed to ensure that family caregivers have leadership roles in developing and implementing mental health policy (MHCC, 2012).

Schizophrenia is one type of chronic and severe mental illness. Persons affected by this disorder experience some of the most challenging symptoms evidenced by any mental illness. These symptoms may include paranoia, hallucinations, delusions, and cognitive changes, which may instigate erratic and dangerous behaviours. Historically, schizophrenia was viewed pessimistically as an inevitable deterioration towards ‘terminal dementia’ (Kraepelin, 1919). Today, schizophrenia is viewed through a recovery-lens as a manageable illness, with affected people capable of leading meaningful and fulfilling lives, despite exacerbations of their illnesses (Deegan in Ridgway, McDiarmid, Davidson, Bayes, and Ratzlaff, 2002, p. 5). Prior to the deinstitutionalization movement (i.e. 1960’s), most individuals with schizophrenia lived in hospitals or other types of institutional settings, where their symptoms and behaviours could be contained. Today, persons with schizophrenia live independently, in community supportive housing, or with their families, with hospitalization being required only in times of acute illness.

With this shift from institutional to community-dwelling, family members of persons with schizophrenia have become instrumental in the organization and delivery of care (Seeman, 1998). In their caregiver roles, family members provide social support through the maintenance of a trusting and loving relationship and engage in day-to-day management, such as cooking, cleaning, housework, and shopping. Family members may also participate in care planning and coordination, crisis management, medication management, transporting to and assisting with appointments, and advocating for services within the health care system. Assuming these responsibilities is often difficult and research shows that caregiving demands lead to caregiver anxiety, depression, sadness, and anger, as well as physical problems including headaches, stomach pains, and problems with sleep (Small, Harrison, & Newell, 2010). Family caregivers for persons with schizophrenia are also shown to have decreased quality of life, increased stress, and several competing priorities such as maintaining their careers or providing care for other family members (e.g. other dependent children or ailing parents) (Sapouna et al., 2013).

Personal Impetus

My experience working as a registered nurse is entirely within psychiatry and predominantly within a schizophrenia program. While transitioning into this professional role, I noticed a great deal of emphasis placed on family-centered care. Patient- and family-centred care is an approach that focuses on meeting the needs of both patients and families, recognizing that the negative effects of illnesses extend to family members (MacFarlane, 2011). While these priorities were articulated within the institution, I did not see family-centered care principles actualized as intended, especially within the realm of nursing care. Instead of truly involving families within the care team, I witnessed only brief exchanges with parents, which most often involved disclosure of a change in patient status, a review of activities while out with family, or parents requesting to consult with a psychiatrist or social worker. The nursing demands of an inpatient psychiatric unit seemed to leave little time to consider the experiences or needs of the family members. When nurses working on the inpatient unit were invited to family meetings, it was rare that they attended because they could not leave their other obligations on the unit.

As a student nurse, I had the opportunity to attend one family meeting. This experience has stuck with me because I was able to reflect more deeply on this individual’s experiences and social dynamics outside of the four walls of the institution. The patient suffered from overwhelming auditory hallucinations and disorganized thoughts that made it difficult for her to articulate her needs clearly. She was quite covert and expressed discomfort when discussing her past trauma. The family meeting was planned just prior to discharge and her sister was present and able to provide the psychiatrist with important historical information. She described reasons why past housing placements had failed, citing a lack of privacy, noise, and male tenants. The sister successfully advocated for changes in the discharge plan, asking that the patient be placed on a wait list for a female-only group home. Without the input of this family member, the care team would not have been able to optimally support the patient through her transition back into the community.

Once I graduated and began working as a registered nurse in psychiatry, I became deeply curious about the experiences of families providing care for adult children with schizophrenia (ACWS). I realized that some of the concerns expressed by parents of ACWS were quite different than those expressed by families I had come across in other clinical settings. The intersection of mental health care and mental health law, issues of competence and insight into illness, and difficult symptoms such as paranoia and auditory hallucinations, for example, make caregiving for ACWS particularly challenging. Family members have told me about their concerns regarding the safety of themselves and their ACWS, and I have heard of parents sleeping with locks on their bedroom doors. Furthermore, parents quite regularly spoke of frustrations regarding the limits of confidentiality when communicating with members of the health care team and the challenges this brought to their lives.

Two particular clinical cases furthered my interest in the experiences of parents providing care for ACWS. The first was the case of a senior woman caring for her adult son. She was quite pleasant each time I saw her, and was kind with staff and grateful for their work. She greeted her son with unconditional positive regard and demonstrated a never-ending commitment to supporting him through decades of his illness. She attended to his needs cheerfully, and would smile graciously when relating the events of a good weekend, or proclaim “we’ll have a better weekend next time” when his weekend was fraught with paranoia and restless nights. The second was the case of a senior woman caring for her adult daughter. This woman’s daughter suffered from the capgras delusion, a false belief that a significant other (i.e. friend, spouse, or parent) has been replaced by an identical-looking imposter (Klein & Hirachan, 2014). I remember her screaming at and berating her mother, not allowing her past the unit entrance when she came to visit. Her mother left the unit in tears, clearly distraught because of the experience and I did my best to comfort her while she expressed her devastation. Witnessing these interactions led me to immerse myself in the literature exploring the phenomenon of caregiving in schizophrenia, while continuing to observe and take a greater interest in the experiences of the parents of patients I would engage with in clinical practice.

Purpose

Family caregiving is vital to the health of persons with schizophrenia, and without this support, many individuals would struggle to maintain their community tenure. While there is an abundance of literature that explores family caregiving in mental illness generally (Chang & Horrocks, 2006; Chien, Chan, & Morrissey, 2007; Hsiao & Tsai, 2014; National Alliance for Caregiving, 2016; Onwumere, Larmonth, & Kuipers, 2016), less is known about the experiences of family caregivers of persons with schizophrenia. Existing literature on the topic includes studies that intermix parent experiences with the experiences of other caregivers (i.e. siblings, spouses, children). Combining the perspectives of all caregivers can distort the particular realities of parent caregivers and make it difficult to compare results across studies. As such, the aim of this research is to explore the experiences of parent caregivers of adult children with schizophrenia (ACWS). The well-being of parents enacting caregiver roles for persons with mental illness is a priority issue for health care providers and policy makers (Mental Health Commission of Canada, 2012). A better understanding of what it means to be a parent caregiver for an ACWS from their perspective will support the development of effective and sustainable interventions tailored explicitly to their needs.

Research Questions

1) According to recent qualitative research literature, how do parents of adult children with schizophrenia (ACWS) experience and describe their caregiver role?

2) How do parents in a large urban Canadian city experience their roles as caregivers for ACWS?

Situating the Researcher

Theoretical scaffolding describes the process of gaining a greater understanding of a phenomenon through progressive knowledge acquisition. Scaffolding can occur through instructional relationships and experiences (Wood, Bruner, & Ross, 1976). Engaging in theoretical scaffolding requires researchers to locate themselves, be aware of what they bring to the research, and consider motivations for conducting the research (Thorne, 2008). Prior to engaging in this thesis work, my understanding of the experience of parent caregivers for ACWS was shaped by many factors. My undergraduate and graduate education at the University of Ottawa and my professional experiences working as a psychiatric and mental health nurse at the Royal Ottawa Mental Health Centre influenced my understanding of the phenomenon. I believe that nurses enact caregiving as part of their professional role. This understanding, of course, is from a nursing lens, which might differ from a parent's point of view.

As a nurse, I recognize that caregiving is facilitated by individual traits, skills, knowledge, and an emotional connection with the care recipient. Caregiving acts aim to address the care recipient's physical, mental, emotional, and social needs (Hermanns & Mastel-Smith, 2012, p. 15). Peplau (1952), a leading nurse theorist, emphasized the centrality of the therapeutic nurse-patient relationship. This relationship is based on trust, respect, empathy, and professional intimacy, as well as appropriate use of power. The therapeutic nurse-patient relationship supports patients in achieving their individually identified health goals (College of Nurses of Ontario, 2006). I consider the therapeutic relationship to be the greatest priority for psychiatric and mental health nurses, and I extend the ‘patient’ to include both the patient in my care and his or her family. With a better understanding of how parents enact and experience caregiving, I will be better able to enter into partnerships with parent caregivers and support my patients with schizophrenia (Cahill, Paley, & Hardy, 2012; Peplau, 1952).

Paradigmatic Stance

I situate my focus of inquiry within the constructivist paradigm. Constructivism has a relativist ontology; realities are apprehended in the form of multiple, intangible mental constructions that are socially and experientially based. They are local and specific in nature, though elements are often shared among individuals. Importantly, the experiences are dependent in their form and content on the individual persons or groups that hold the constructions (Lincoln & Guba, 1985). In this thesis, you will see how the experiences of each parent caregiver are distinct, but that there are parts of these experiences that are recognized and described by other caregivers. I chose the constructivist paradigm because I wanted my research to reflect the realities of the parents involved.

The methodology of constructivism is hermeneutical and dialectical. Hermeneutics is the act of interpretation and an approach to data analysis that highlights how prior understanding of a phenomenon configures the interpretive process (Appleton & King, 1997; Schwandt, 1997). Dialectical logic brings forth conflicting thoughts and perspectives of a phenomenon by seeking out convergent and divergent ideas from the study participants (Appleton & King, 1997; Denzin & Lincoln, 2005). During the interviews, I sought similar and conflicting perspectives and encouraged the parents to share their stories and experiences freely by asking open-ended questions and engaging them in conversation-like interviews. As the investigator, I shared in the process of constructing the emergent findings (Lincoln & Guba, 1985).

Approaching this study from a constructivist lens allows for an understanding of the subjective realities of parents who are caregivers for ACWS. Caregiving is enacted in many ways and not all caregivers experience their role in the same manner (Lazarus & Folkman, 1984). As such, this paradigmatic position allowed me to appreciate individual parents' realities and experiences, and also recognize the commonalities they shared. The parents included in this study expressed how important it was for them to share their personal stories and add to our understanding of the topic. They hoped that this research might improve the experiences of other families undergoing similar experiences. I recognize that my appreciation of this phenomenon is informed through my own clinical experiences and examination of available literature. Through exploring caregiving experiences of parents of ACWS explicitly, I expect to enhance my own understanding and contribute to the existing body of knowledge regarding parent caregiving experiences in schizophrenia.

Organization of the Thesis

This thesis includes two studies and is presented in manuscript style. In Chapter One, I provided a brief introduction to my topic while explaining my personal impetus for the research and my paradigmatic stance. The remainder of the thesis is organized into four chapters. In Chapter Two, I provide background information on the concepts included in this Thesis. Chapter Three contains the first manuscript titled, "Exploring the Experiences of Parent Caregivers in Schizophrenia: A Qualitative Evidence Synthesis", which is a synthesis of qualitative literature on the topic. Chapter Four presents the findings of a qualitative study exploring the experiences of parents caring for their ACWS in a large urban Canadian city. This manuscript is titled, “Exploring the Experiences of Parent Caregivers in Schizophrenia: A Qualitative Study.” The manuscripts from both Chapter Three and Four are prepared for submission to two academic peer-reviewed psychiatric nursing journals. Chapter Five summarizes the thesis and includes an integrated discussion situating the findings within the broader literature. Implications for practice, policy, education, and research are presented.

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Chapter Two

Overview of the Literature

Overview of the Literature

Chapter two provides an overview of the main concepts discussed in this thesis. Specifically, the concepts of schizophrenia, family, caregiving, and family caregiving are reviewed, and relationships between these concepts are explored.

Schizophrenia

The National Institute of Mental Health ([NIMH], 2016) describes schizophrenia as a chronic and severe mental illness affecting how someone thinks, feels, and behaves. Symptoms of the illness fall within three broad categorizations: positive, negative, and cognitive symptoms (NIMH, 2016). Positive symptoms include hallucinations, delusions, or thought disorders. Negative symptoms are associated with disruptions in normal emotions or behaviours, and include a flattened affect, reduced feelings of pleasure, difficulty beginning or sustaining activities, or reduced speech. Finally, cognitive symptoms, which might be subtle or severe, include difficulties with executive functioning (i.e. planning and decision making), focus, attention, or memory (NIMH, 2016).

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), a diagnosis of schizophrenia requires two or more Criterion A symptoms to be present for at least one month. The symptoms must include a delusion, hallucination, or disorganized speech. Other symptoms might include grossly disorganized or catatonic behaviour, and negative symptoms (American Psychiatric Association, 2013). Additionally, there must be a decrease in the individual’s level of functioning and signs of the illness must persist for at least six-months (American Psychiatric Association, 2013).

The exact etiology of schizophrenia is unknown, though researchers suggest a combination of genetics, brain chemistry, and environmental factors (Howes & Kapur, 2009).

Risk factors include obstetric complications, stress and trauma, drug use, and genetic predisposition (Howes & Kapur, 2009). From a neurochemical perspective, experts believe that symptoms of schizophrenia are produced through dysregulation of the dopamine system (Fusar-Poli & Meyer-Lindenberg, 2012). Many medications used to treat the illness work to address dysregulation through dopamine receptor agonists, antagonists, or partial agonists. Most recently, overexpression of gene version C4A in chromosome six was identified by scientists as being the strongest known genetic risk factor associated with the development of schizophrenia (Sekar et al., 2016). Synaptic pruning is a normal process occurring in late teens and early adulthood whereby the C4A protein marks certain synapses for destruction. Unnecessary neural connections are removed in order to streamline the brain's functioning. In schizophrenia, scientists propose that too many of these proteins are switched on leading to excess synaptic pruning and resulting in symptoms we identify as belonging to schizophrenia. This ground-breaking genetic study has implications for clinical tests, early detection, new treatments, and even prevention (Sekar et al., 2016).

Illness trajectory

Schizophrenia typically develops in young people between the ages of 15 and 25 years old – a critically important period of biological, social, and psychological development (Canadian Psychiatric Association & Schizophrenia Society of Canada, 2007). Prior to experiencing a first episode psychosis (i.e. when a person first exhibits clear signs of psychotic behaviour), individuals with schizophrenia typically pass through a prodromal period when a number of early, but non-specific, symptoms of the illness occur. These symptoms often include deterioration of performance in school or work, social withdrawal, moodiness, fear, anxiety, aggressiveness, changes in personal care and hygiene, or a lack of interest and motivation

(Canadian Psychiatric Association & Schizophrenia Society of Canada, 2007). Once a diagnosis is made, a person living with schizophrenia will fluctuate between three distinct phases: the acute phase, stabilization, and the stable (or chronic) phase (American Psychiatric Association, 2013). The acute phase may develop gradually or suddenly. Symptoms are often severe and individuals require professional help. During stabilization, treatment is initiated (or re-initiated) and there is a reduction in acute symptoms. Finally, in the stable phase, acute symptoms are managed, but some functional disability may persist (American Psychiatric Association, 2013). Functional disability can limit many aspects of independence, ranging from activities of daily living to attaining (and more importantly, sustaining) employment or education.

Management

Experts recommend that management strategies be initiated as early as possible when a first episode psychosis occurs (Yung & Barnaby, 2013; Diaz-Caneja et al., 2015). Early interventions must be specialized and comprehensive, and include easy and rapid access to services, provide educational and vocational plans, and address comorbidities. Biopsychosocial care plans should include pharmacotherapy, individual and group therapies, and family psychosocial interventions (Nolin, Malla, Tibbo, Norman, & Abdel-Baki, 2016). Experts advocate for early intervention because deterioration in health and functioning is not solely related to biological processes. Instead, psychosocial factors present during this period also contribute to negative outcomes. A reduction in the duration of untreated psychosis (DUP), through early intervention and specialized services, is said to improve outcomes for persons living with schizophrenia and their families (Diaz-Caneja et al., 2015; Yung & Barnaby, 2013). In their recent systematic review and meta-analysis evaluating DUP as a predictor of long-term outcomes in schizophrenia, Penttilä and colleagues (2014) found that a longer DUP correlated with poor symptom outcomes, greater symptom severity, lesser likelihood of remission, and poor social and global functioning. Furthermore, the authors concluded that early intervention services have a positive effect on the long-term course of the illness (Penttilä, Jääskeläinen, Hirvonen, Isohanni, & Miettunen, 2014).

In addition to antipsychotic medication, interventions include a combination of psychosocial approaches, such as peer support, group therapies, family therapies, and counselling such as cognitive behavioural therapy. A number of symptoms can be addressed through medication, though taking a biopsychosocial approach is key to addressing all aspects of the illness. This approach leads to improved cognitive abilities, increased energy, resumption of social relationships, and engaging in functional activities, such as hobbies or work (Kuhnigk, Slawik, Meyer, Naber, & Reimer, 2012).

Recovery

Recovery in schizophrenia, the ultimate goal of management strategies, is a concept that has evolved considerably over the last hundred years (Kraepelin, 1919; Frese, Knight, & Saks, 2009). Simply defined, recovery involves a new and valued sense of integrity and purpose within and beyond one’s disability (Deegan in Ridgway, McDiarmid, Davidson, Bayes, & Ratzlaff, 2002). Recovery encompasses two interrelated concepts: the *process* and the *outcome*. The process is when one is engaged, for example when someone is said to be “recovering”, and the *outcome* is the end point or goal of recovery, which considers factors such as symptom management and improved functioning (Glynn, Cohen, Dixon, & Niv, 2006).

From a patient perspective, recovery is described as a process beginning with improvements in thinking and feeling, which progresses to reconnecting with their environment and social supports, and finally, rediscovering the ability to focus outward on the world around them (Forchuk, Jewell, Tweedell, & Steinnagel, 2003). Often this will necessitate a reduction of symptoms, functional improvement, and normalization (Jacobson, 2004). For many persons with schizophrenia, working, volunteering, or returning to school are important and meaningful recovery goals (Deegan in Ridgway, McDiarmid, Davidson, Bayes, & Ratzlaff, 2002). These goals can be facilitated through working with health and social services providing supported employment, social skills training, and life skills training (Canadian Psychiatric Association & Schizophrenia Society of Canada, 2007). Family psychoeducation and support groups serve to increase community tenure and may improve social functioning, decrease symptoms in persons with the illness, and reduce family burden; all important considerations in recovery.

Challenges Associated with the Management of Schizophrenia

Existing strategies used to manage schizophrenia are fraught with challenges. As the primary pharmacologic option, antipsychotic medications are routinely prescribed to persons with schizophrenia. These medications are available in oral and injectable forms and are classified as either first-generation antipsychotics (FGA) or second-generation antipsychotics (SGA). FGA medications are known to have a high rate of extrapyramidal side effects. These are drug-induced movement disorders such as muscle rigidity, bradykinesia (slowness of movement), dystonia (continuous spasms and muscle contractions), tremor, akathisia (motor restlessness), and tardive dyskinesia (irregular, jerky movements) (Blanchet, Parent, Rompre & Levesque, 2012; Muench & Hamer, 2010). SGAs are more commonly prescribed because they cause fewer side effects and are shown to be more effective in treating negative, cognitive, and depressive symptoms than FGAs (Canadian Psychiatric Association & Schizophrenia Society of Canada, 2007). Unfortunately, SGA medications are also associated with unwanted side effects, such as weight gain, metabolic syndrome, and cardiovascular disease (Muench & Hamer, 2010).

As a result of the complicated nature of antipsychotic treatment and the prevalence of side effects, medication non-adherence is common. When a person with schizophrenia stops taking their antipsychotic medications, they often experience an exacerbation of their illness – most individuals with schizophrenia require maintenance of antipsychotic therapy to sustain an optimal level of mental stability. While there exists a wide range of estimates, CATIE investigators (Clinical Antipsychotic Trials of Intervention Effectiveness) found an overall medication discontinuation rate of 74% within 18 months (n= 1493) (Lieberman et al., 2005) and Dibonaventura and colleagues (2012) found that only 42.5% of 876 people reported complete adherence with their medication regimen (Dibonaventura, Gabriel, Dupclay, Gupta, & Kim, 2012). When antipsychotic medications are not taken properly, there is an estimated 90% chance of relapse within one year (Canadian Psychiatric Association & Schizophrenia Society of Canada, 2007). Persons with schizophrenia are often monitored closely for medication adherence to avoid exacerbation of psychotic symptoms, and for people admitted to hospital, nurses assume this responsibility. For persons living in the community, support for medication adherence might include outpatient service providers or other less formalized supports, such as family members.

Complicating the illness management process for persons with schizophrenia is the common occurrence of comorbid conditions, such as diabetes or heart disease. Careful monitoring of mental and physical health is essential due to the combined effects of lifestyle factors and medication side effects on the development of metabolic comorbidities (e.g. obesity and hyperlipidemia) (Padmavati, McCreadie, & Tirupati, 2010). In additional to physical comorbidities, persons with schizophrenia commonly engage in substance use and misuse (Padmavati, McCreadie, & Tirupati, 2010). Approximately 40% of people with psychosis misuse substances at some point in their lifetime, which is at least twice the rate of the general population (National Institute for Health and Care Excellence [NICE], 2011), and research suggests that substance use can worsen symptoms (Haddock, Eisner, Davies, Coupe, & Barrowclough, 2013).

Finally, management of the complex physical and mental health needs for people with schizophrenia often requires access to multiple services provided across many settings. It is known that our healthcare system lacks continuity and this fragmentation creates difficulties for individuals and their families trying to navigate services (Digel Vandyk, Graham, VanDenKerkhof, Ross-White, & Harrison, 2013). Uncoordinated care can result in suboptimal outcomes, and those who reach scattered services are unlikely to engage appropriately in care (Poremski, Sagayadevan, Wang, Lum, Subramaniam, & Ann, 2016). It is also not uncommon for healthcare practitioner, patient, and family to prioritize different aspects to care. For example, a clinician might prioritize treatment of persistent negative symptoms, the family might be more concerned with agitation, while the patient might consider the side effects of the medication unbearable (Weiden, 2003).

In summary, the management of schizophrenia requires adherence to antipsychotic medications that are known to cause unpleasant and unwanted side-effects and worsening physical health. Furthermore, access to multiple services, offered within a fragmented healthcare system, is problematic. To mitigate potential challenges to management, persons with schizophrenia often receive care from a team of caregivers, which include professional supports, such as psychiatrists and nurses, as well as family, friends, or neighbours.

Family

The family is a unit of two or more individuals who, through the context of their relationships, support one another in various roles and responsibilities (Wright & Leahey, 2014).

Several definitions of family exist, including: 1) a group of people related by blood or marriage (Oxford Dictionary, 2017b); 2) a group consisting of parents and their children living together as a unit (Oxford Dictionary, 2017b); 3) the basic unit in society traditionally consisting of two parents rearing their children (Merriam-Webster Dictionary, 2017); and 4) any of various social units differing from but regarded as equivalent to the traditional family (i.e. a single-parent family) (Merriam-Webster Dictionary, 2017). ‘Parents’ are a person’s father or mother (Oxford Dictionary, 2017c), and while a ‘child’ is often viewed as a young person, below the age of puberty or legal age of majority (Oxford Dictionary, 2017d), a child can also be a son or daughter of any age (Oxford Dictionary, 2017d). The concept of family continues to evolve over time, and there is no universally accepted definition. Descriptions vary by discipline and may include conceptualizations that have roots in legal (i.e. relationships through blood ties, adoption, guardianship, or marriage), biological (genetic biological networks among and between individuals), sociological (groups of people living together with or without legal or biological ties) and psychological (groups with strong emotional ties) considerations (Kaakinen, Coehlo, Steele, Tabacco, & Harmon Hanson, 2015, p.4). Although family may refer to any self-defined two or more individuals who depend on one another for physical, emotional, and economic support (Kaakinen, Gedaly-Duff, Coehlo, Harmon Hanson, 2010), for this Thesis, I am most interested in the particular family composition of parent and child.

In most western societies, it is common for parents to provide support to their children as they gain autonomy and eventually move away from home and establish their own lives, careers, relationships, and financial independence (Vianden & Ruder, 2012). Once adulthood is attained, the parent-child relationship becomes reciprocal, with parents and children trading emotional, practical, and financial support over the life course (Lye, 1996), and a balance is struck between obligation and independence (Aldous, 1995).

Adult-child and parent relationships become strained when there are conflicting expectations of obligation and independence (Aldous, 1995). Obligation stipulates that adult children and parents should help and care for one another throughout the lifespan, while independence requires adults to assume responsibility for their own well-being (Lye, 1996). When an adult child is diagnosed with a life-altering chronic condition (such as schizophrenia), these expectations and normative assumptions are interrupted. In some cases, adult children are unable to consistently move toward independence, and their ability to uphold obligations are also diminished (Mausbach et al., 2008). Ill family members are often less able to engage in routines and rituals considered to be important elements of family health. When illness and symptom management are prioritized over typical family functioning, further stress is placed on the unit, and family dynamics can be fundamentally altered because of caregiving experiences (Chang & Horrocks, 2005; Crespo, Santos, Canavarro, Kielpikowski, Pryor, & Feres-Carneiro, 2013; McAuliffee, O'Connor, & Meagher, 2014).

Caregiving

When exploring the concept of caregiving, it is important to first define related terms. While there is no shortage of literature exploring 'caring' (Leinninger, 1984; Watson, 1979; Fawcett, 1984; Swanson, 1991; Rogers, 1970), the term is criticized for being ambiguous, hard to define, and lacking definitional consensus (Cook & Peden, 2017). In the most basic sense, referring to the Oxford Dictionary (2017a), we see the broadness of definitions used for caring, which include displaying kindness and concern for others, as well as the work or practice of looking after those unable to care for themselves. In contrast, the term 'caregiving' is more consistently defined, and includes an element of attention to the needs of others (Oxford University Press, 2017), whether that be persons unable to look after themselves adequately and requiring professional support in the provision of health or social care, or the needs of a child, elderly person, or others (Oxford University Press, 2017, n.p.).

To build upon this basic understanding, it is important to explore conceptual and theoretical writings that attempt to explain caregiving, and several models, frameworks, and theories exist for this purpose. Here, I elaborate on the conceptual writings of Hermanns and Mastel-Smith (2012), Conde-Sala and colleagues (2010), Hunt (2003), Tsai (2003), and Lazarus and Folkman (1984). First, I provide a brief summary of their works and then describe how each of these contributes to my understanding of the concept caregiving.

Hermanns and Mastel-Smith (2012) used a hybrid qualitative model of concept development to analyze caregiving, which combined theoretical, fieldwork, and analytical phases. They described caregiving as both an act and a process that is evaluated in terms of its implication or outcomes. Their concept analysis yielded the following definition, which best resonates with my conception of caregiving:

> Caregiving is the process of helping another person who is unable to do for themselves in a holistic (physically, mentally, emotionally, and socially) manner. Caregiving is facilitated by certain character traits, emotions, skills, knowledge, time, and an emotional connection with the care recipient (Hermanns & Mastel-Smith, 2012, p. 15).

Conde-Sala and colleagues (2010) proposed a model that highlights the multidimensional nature of stress factors and interventions on caregiver wellbeing. Primary stressors (those associated with the care recipient) need to be considered, but more importantly, caregiver-associated variables are shown to have a greater influence on burden. Contextual variables (i.e.

family relationships, relationship history, living with the patient, gender of caregiver / patient, time spent caregiving), primary stressors (those related to the care recipient), and secondary stressors (i.e. family conflicts, difficulties at work, or financial difficulties) all contribute to caregiver outcomes. Additionally, the type and effectiveness of interventions provided (i.e. social support, community resources, and treatments) further contribute to (either positively or negatively) caregiver wellbeing (Conde-Sala, Garre-Olmo, Turro-Garriga, Vilalta-Franch, & Lopez-Pousa, 2010).

Hunt's (2003) work aimed to clarify the consequences of caregiving. Positive consequences of caregiving included caregiver esteem, uplifts of caregiving, caregiver satisfaction, finding or making meaning through caregiving, and gain in the caregiving experience. Negative consequences of caregiving included caregiver burden, hassles of caregiving, caregiver strain, and caregiver stress (Hunt, 2003). Hunt's conceptualization explains how a caregiver's perceptions of their caregiving experiences are facilitated by their innate qualities, and how caregiving and one's views of it may change over time.

Tsai's 2003 Middle Range Theory of Caregiver Stress is based on the Roy adaptation model (Roy, 1984). In this theory, caregiving is seen as a process along a trajectory, with both static and dynamic elements. This theory highlights the differences between individual caregivers in terms of their adaptation and ability to cope with various amounts of stimuli – what might be considered overwhelming for one caregiver may be manageable for another.

Similarly, Lazarus and Folkman (1984) described in their Transactional Model of Stress and Coping, the transaction between an individual and their environment. Specifically, they explained how one appraises individual stressors and the influence these stressors have on their ability to cope. Appraisal is not necessarily a conscious process; it is highly subjective and personal. During primary appraisal, a caregiver evaluates the significance of a situation and judges it to be irrelevant, benign-positive, or stressful. If the situation is perceived as stressful, additional appraisals of harm, loss, threat, or challenge take place. In secondary appraisal, the caregiver evaluates internal coping options (e.g. determination) or external coping options (e.g. finances, relational support), as well as available resources for dealing with the stressor. At this point, reappraisal occurs and the caregiver reconsiders both available coping resources and the stressor (Lazarus & Folkman, 1984). Coping refers to a person's constantly changing cognitive and behavioural efforts to manage specific demands appraised as taxing, or exceeding the person's available resources (Lazarus & Folkman, 1984, p. 141). Lazarus and Folkman (1984) add the distinction between two types of coping: problem-focused coping and emotion-focused coping. Managing difficult symptoms provides a useful illustration of these concepts relevant to caregiving. Problem-focused strategies aim to manage or alter the problem causing the distress; for example, advocating for an earlier appointment with a health care provider based on symptom severity. Emotion-focused coping is directed at regulating one's emotional response to the problem, and might be enacted through deep-breathing, remaining calm, and empathizing with the care recipient. Importantly, this model, like Tsai's (2003), emphasizes that caregivers' abilities to cope are not only variable, but also modifiable.

In summary, Hermann's conceptualization defines caregiving from a holistic perspective and emphasizes that the act of caregiving is influenced by qualities of the caregiver, however context and its effect on caregiving are not addressed. Conde-Sala and colleagues (2010) identify primary, secondary, and contextual variables, as well as effects of interventions, on caregiver outcomes. These conceptualizations provide a understanding of the personal and contextual factors influencing caregivers. Hunt's conceptualization highlights the negative and positive consequences of caregiving. Tsai's theory (2003) describes how coping abilities of caregivers are influenced by their level of adaptation, while Lazarus and Folkman introduce the importance of appraising stressors when determining which coping mechanism to use in the context of caregiving. Together, these models, theories, and frameworks provide a conceptual foundation upon which I base my understanding of caregiving and its complexities.

Family Caregiving

Family members provide various types of care to one another across the lifespan, both in times of health and illness. The typical family life cycle is described as consisting of the following phases, 1) becoming independent, 2) becoming partners, 3) becoming parents, 4) living with adolescents, 5) launching independent children, and 6) grand-parenting in later life (Alessi, 2000; McGoldrick & Carter, 1982). During each of these phases, family members engage in caregiving and care receiving roles, which are considered to be a part of normal family functioning. When a member of the family becomes ill, caregiving responsibilities increase. Additional caregiving responsibilities may be needed and the type of care provided may change.

The term "family caregivers" typically refers to unpaid care providers to family or non-family members (i.e. friend or neighbour) during times of illness or functional impairment (Blum & Sherman, 2010; Feinberg et al., 2011; Schumacher, Beck, & Marren, 2006). Statistics Canada (2015) defines family caregivers as any person aged 15 years and over who provide help or care to a family member with a long-term health condition (either physical or mental), within the past 12 months Over eight million Canadians provide care for a chronically ill or disabled friend or loved one (Statistics Canada, 2012), and nearly half of Canadians have provided care to a family member or friend with a long-term health condition, disability, or aging need at some point in their lives (Statistics Canada, 2012). Support services in the community are often inadequate to meet the health care needs of individuals, and as such, family caregivers are shown to provide more than 80% of the care necessary to maintain the health and well-being of their loved one (Home Care Ontario, 2015). Formerly, family caregivers were referred to as ‘informal caregivers’; however, the use of this term is discouraged because it diminishes and invalidates the role, nature, and intensity of care provided by family caregivers (Home Care Ontario, 2015).

Family caregivers are an important source of social support, which is defined as the “assistance (financial aid, intangible emotional help) and protection (shielding people from adverses effects) given to others” (Langford, Bowsher, Maloney, & Lillis, 1997, p. 95). Social support is often classified in terms of emotional, appraisal, instrumental, and informational support, and each form is provided by family caregivers (Langford, Bowsher, Maloney, & Lillis, 1997). *Emotional support* refers to the provision of care, empathy, love, and trust (House, 1981). *Appraisal* includes communication of information relevant to self-evaluation (House, 1981) and affirmation of the appropriateness of acts or statements made by an individual (Kahn & Antonucci, 1980). *Instrumental support* is the provision of goods, services, or aid (House, 1981; Tilden & Weinert, 1987), while *informational support* is when information is provided to another during a time of stress, which can assist with problem-solving and decision making (House, 1981; Tilden & Weinert, 1987).

Family caregivers report decreased quality of life as a consequence of their role and responsibilities, and quality of life is mediated through a number factors including time spent caregiving, symptom severity of the care recipient, and psychological distress experienced by the caregiver (Kate, Grover, Kulhara, & Nehra, 2014; Quah, 2014). Social consequences, such as less engagement in activities, increases in household arguments, and economic difficulties are all contributing factors to reduced quality of life (Awad & Wallace, 1999; Pshuk & Pshuk, 2015; Kate, Grover, Kulhara, & Nehra, 2014; Sapouna et al., 2013). Healthy coping skills are essential to mitigate the stresses associated with caregiving, and quality of life is negatively influenced by a lack of coping skills and the resulting inability to manage (Kate, Grover, Kulhara, & Nehra, 2014). Furthermore, increased self-efficacy is correlated with caregivers being able to identify positive aspects of their role (Semiatin & O'Connor, 2012), and these positive experiences and feelings are said to protect caregivers from developing known negative psychological and physical consequences of caregiving (Semiatin & O'Connor, 2012). Though the positive aspects of caregiving in the context of mental illness are not often discussed (Awad & Voruganti, 2008), in a recent literature review, the authors identified caregiving gains, such as clarity about priorities in life, strengthened relationships with the care recipient, and a greater sense of inner strength (Kulhara, Kate, Grover, Kulhara, & Nehra, 2012).

Family Caregiving in Schizophrenia

Family caregiving in schizophrenia is a shared experience effecting the entire family unit (McAuliffe, O'Connor, & Meagher, 2014; Huang, Hung, Sun, Lin, & Chen, 2009; Wiens & Daniluk, 2009). While often perceived as negative, the experience of family caregiving can be improved through reducing the total number of hours spent caregiving, increasing the family caregiver's coping capacities, and effectively managing symptoms of the care recipient (Schene, Wingaarden, & Koeter, 1998). Schene, Wingaarden, and Koeter (1998) identified four domains of family caregiving in schizophrenia, including tension, supervision, worrying, and urging. *Tension* refers to the strained interpersonal relationship between the individual and their family. *Supervision* refers to the caregiver's responsibilities of ensuring that their loved one take their medication, have adequate sleep, and not engage in risky behaviours. *Worrying* includes difficult thoughts and concerns about their loved one's health, safety, or the quality of health care received. Finally, *urging* refers to the caregivers' attempts to activate, motivate, or stimulate their loved one to take care of themselves. Family members may urge their loved one to engage in activities of daily living, such as eating or bathing, or community involvement, such as attending groups, working, or volunteering (Schene, Wingaarden, & Koeter, 1998).

The responsibility of providing care for a family member with schizophrenia is at times so intense that families report engaging in the caregiving role 24 hours a day, seven days a week (McAuliffe, O'Connor, & Meagher, 2014). Lifestyle adjustments are necessary, and social, leisure, and even work activities formerly enjoyed by families are disrupted (Chadda, 2014; McAuliffe, O'Connor, & Meagher, 2014). Family members experience a great deal of psychological distress as they try to respond and cope with the symptoms of the illness (Wiens & Daniluk, 2009). Those in most frequent contact with the person with schizophrenia report the highest levels of burden (Asen, 2002; Awad & Voruganti, 2008). Negative and disruptive symptoms, such as behavioural disturbances, greatly increase caregiver distress (Awad & Voruganti, 2008) especially when there is a risk or history of violence toward family members (Huang, Hung, Sun, Lin, & Chen, 2009).

The symptoms of schizophrenia also contribute to increased family conflict (Huang, Hung, Sun, Lin, & Chen, 2009; McAuliffe, O'Connor, & Meagher, 2014; Wiens & Daniluk, 2009). Marital relationships suffer because of differing opinions leading to argument, stress induced through symptoms and illness management, or not being able to spend quality time together as a couple (McAuliffe, O'Connor, & Meagher, 2014). Persons with schizophrenia may have difficulties getting a job, experience financial difficulties, and have trouble partaking in household chores, which can lead to conflict. Furthermore, some family members may misattribute negative symptoms to laziness and may harbour resentment or anger as a result of this misunderstanding (Huang, Hung, Sun, Lin, & Chen, 2009). Negative symptoms including poor hygiene, lack of initiative, social withdrawal and poor social functioning, are known to create friction within the family (Huang, Hung, Sun, Lin, & Chen, 2009).

Parents, frequently mothers (Awad & Voruganti, 2008), are the most common primary caregivers for persons with schizophrenia (Chen, Gearing, DeVylder, & Oh, 2014). Depending on the family makeup, parents may have caregiving responsibilities to other children or older parents. Given the chronicity of schizophrenia, some parents continue to provide care over the course of their ACWS illness and into older age (Awad & Voruganti, 2008). As a result of caregiving, parents experience significant costs to their own physical and mental health (Small, Harrison, & Newell, 2010), including psychological distress and trauma (McAuliffe, O’Connor, & Meagher, 2014). Reconciling the competing priorities of ensuring that their ACWS has psychiatric stability and being a parent can be challenging and negatively influence the parent’s wellbeing (Chadda, 2014). For example, when parents become responsible for checking in daily to see if their child has taken his or her medication, this not only has the potential for stress and conflict, but can also transform the parent-child roles and relationships (Wright & Leahey, 2014). Parents begin to prioritize illness management, such as day-to-day care, supervising medications, attending to appointments, and looking after financial needs. These changes alter the parent-child relationship and have a ripple effect on other family members and their relationships (Chadda, 2014).

Conclusion

Parents provide caregiving for ACWS as they move through acute, stable, and chronic phases of the illness trajectory. The caregiver has a number of task-based responsibilities including day-to-day care, medication supervision, attending appointments, and financial management. Importantly, parents are also a consistent source of social support for their ACWS.

Caregiving responsibility and the effects of symptoms can be distressing for caregivers and cause conflict within families. Theoretical constructions and frameworks are helpful to better understand how these caregivers appraise, cope, or adapt to their caregiving role. Collectively, however, studies exploring parent caregivers' experiences in the context of schizophrenia are limited (Huang, Hung, Sun, Lin, & Chen, 2009; McAuliffe, O'Connor, & Meagher, 2014). While researchers have examined *family* experiences, few studies have explored the experiences of *parents* specifically (Wiens & Daniluk, 2009; Yen, Teng, Huang, Ma, Lee, & Tseng, 2010). Researchers appear to intermix parent caregiver experiences with others, such as spouses or children, and yet it is clear that there are specific considerations regarding the nature of the parent-child relationship that warrant investigation. To address this knowledge gap, the literature review was extended to include a qualitative evidence synthesis of parent caregiving experiences in schizophrenia (Chapter Three) designed to tease out parent voices specifically from the existing literature.

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Chapter Three

Exploring the Experiences of Parent Caregivers in Schizophrenia:

A Qualitative Evidence Synthesis

This chapter is an unpublished manuscript formatted for submission to an academic peer-reviewed psychiatric nursing journal

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Abstract

Literature exploring caregiver experiences in the context of schizophrenia exists, yet authors appear to intermix samples with parent and other caregivers (i.e. siblings, spouses, or children). As such, it is difficult to isolate parent experiences of caregiving, which may differ because of the nature of the parent-child relationship. This was a qualitative evidence synthesis on the experiences of parent caregivers for adult children with schizophrenia. All standard systematic review procedures were followed, including double screening, data extraction, and quality appraisal. Content analysis was used to synthesize and interpret the findings from the five studies included. Five distinct categories were identified: *Access, Availability, and Appropriateness of Resources', 'Loss', 'Psychological Distress', 'Effects on Family',* and *'Framing the Experience.'* Parent caregivers need help navigating available services and support for their own mental and physical health needs. Furthermore, the needs of parent caregivers of ACWS should be given greater attention in clinical practice.

Keywords: adult children, caregivers, parents, qualitative research, schizophrenia.

Background

The typical age of onset for schizophrenia is between late adolescence and early adulthood (Gogtay, Vyas, Testa, Wood, & Pantelis, 2011). At this time, individuals are transitioning through their senior years of high school or have recently graduated and are embarking on college, university, or joining the workforce. The symptoms of schizophrenia can have devastating effects on functionality during these life stages, through interrupted education, failure to attain and sustain work, and inability to live independently. The illness persists into adulthood and old age, and individuals with schizophrenia commonly depend on others for social support and housing. Less than 20% of persons with schizophrenia live alone in the community and almost half live with family members who support their health and wellbeing (Awad & Voruganti, 2008; Tsai, Stroup, & Rosenheck, 2011).

Outpatient mental health services, which provide the majority of psychiatric care, are focused on acute treatment and lack resources to address basic daily needs of persons with schizophrenia. As such, family members participate in the provision of ongoing physical, mental, social, and psychological care (Glynn, Cohen, Dixon, & Niv, 2006). Parents who live with adult children with schizophrenia (ACWS) facilitate day-to-day activities (cooking, cleaning, and housework), care planning and coordination, medication management, transportation, and appointments. Caregiving roles shift from an emphasis on involvement in medical care during acute illness, to social and psychological support during stable phases (Glynn, Cohen, Dixon, & Niv, 2006; Janardhana, Raghunandan, Naidu, Saraswathi, & Seshan, 2015). Moreover, parents manage crisis situations and communicate with health and legal professionals (Small, Harrison, & Newell, 2010). Reconciling the competing priorities of ensuring psychiatric stability and being a parent is challenging (Chadda, 2014).

Researchers have explored aspects of family caregiving in schizophrenia. Investigation of family resilience (Bishop & Greeff, 2015), burden and coping (Caqueo-Urizar et al., 2014; Hsiao & Tsai, 2014), difficult symptoms involving family members (Onwumere, Learmonth, & Kuipers, 2016), role distress and quality of life (Quah, 2014), and navigation of the mental health care system exist (Wainwright, Glentworth, Haddock, Bentley, & Lobban, 2015; Jack-Ide, Uys, & Middleton, 2013). Findings suggest that family caregivers face many challenges affecting all aspects of their lives (Quah, 2014). They rarely seek care for their personal needs (Chadda, 2014), and their health and wellbeing suffer because of their caregiving responsibilities (Kate, Grover, Kulhara, & Nehra, 2014; Sapouna et al., 2013). Furthermore, parent caregivers are shown to have decreased overall quality of life related to less engagement in social outings and activities, more frequent disagreement and fighting in their households, increased rates of depression, economic difficulties, delays or cancellations of vacation plans, and declines in work or school performance (Awad & Wallace, 1999; Pshuk & Pshuk, 2015; Kate, Grover, Kulhara, & Nehra, 2014; Sapouna et al., 2013).

Purpose

Qualitative studies exploring the experiences of parent caregivers for ACWS exist, which highlight the experiences of parent caregivers. However, findings have yet to be synthesized across studies. Synthesis studies aim to identify, evaluate, and summarize the findings of all relevant literature, thereby making the available evidence more accessible to decision makers, researchers, and other stakeholders. We have noted that authors tend to intermix parents with other forms of family caregivers or include various types of severe and persistent mental illness into their studies (Bauer, Koepke, Sterzinger, & Spiessl, 2012; Bishop & Greeff, 2015; Wainwright, Glentworth, Haddock, Bentley, & Lobban, 2015). While family caregivers may share common experiences, the nature of the parent-child relationship is different (e.g. parents are responsible for rearing and the relationship is expected to move from total dependence to independence of the child) and warrants investigation. A rigorous review is needed to shed light on the specific experiences of parents of ACWS to inform resources aimed at supporting this population. The purpose of this study was, therefore, to explore and synthesize the caregiving experiences of parents of ACWS. The specific research question was: According to recent qualitative research literature, how do parents of adult children with schizophrenia (ACWS) experience and describe their caregiver role?

Methods

Design

This was a Qualitative Evidence Synthesis (Grant & Booth, 2009) modeled on the Joanna Briggs Methodology for Qualitative Systematic Reviews (JBI, 2014). Qualitative studies, by virtue of their design and philosophical underpinnings, give representation to the subjective nature of a phenomenon (Lincoln & Guba, 1985). Qualitative Evidence Synthesis integrates findings from qualitative studies and looks for themes or constructs that exist across individual qualitative studies (Grant & Booth, 2009). The JBI methodology allows researchers to answer a specific research question through reviewing the evidence in a systematic manner. The research team had expertise in schizophrenia, mental health, caregiving, qualitative research, and systematic review methodologies.

Selection Criteria

The PICo (Population, phenomena of Interest, and Context) strategy (Stone, 2002; JBI, 2014) was used to delineate eligibility criteria (Table 1). Full-text and peer-reviewed qualitative and mixed-methods studies, published in English, were included if they explored parental caregiving experiences in schizophrenia or schizoaffective disorder. Unpublished or grey literature, abstracts, theses, dissertations, books, and conference summaries were excluded.

Search Strategy

We designed a three-step strategy. First, within the MEDLINE, PsycINFO, and CINAHL databases, we searched with the keywords: schizophrenia, parents, and caregiving. This helped us to identify the following relevant MESH headings: schizophrenia, psychotic disorders, schizophrenia spectrum and other psychotic disorders, caregivers, parents, fathers, mothers, and single parent. Second, we tailored searches specifically for each database using these MESH headings and a predetermined set of keywords (See Table 2 for an example search strategy). Third, we continued to look for new research published on the topic and included any relevant studies identified (i.e. hand-search, reviewing reference lists of selected articles, etc.). The search strategy was developed with the assistance of two library scientists. One library scientist aided in clearly defining concepts and exploring potential search strategies. The other library scientist helped narrow concepts and identify keywords and MESH headings.

Study Selection

After removing duplicate citations, studies were selected using a two-level screening process. Two reviewers conducted first-level screening (LY, LM) by title and abstract. During this initial screening, studies were excluded, kept, or marked as unsure based on their congruence with the eligibility criteria. The two reviewers independently screened all citations at this stage and a meeting was held to resolve conflicts in selection. Second-level screening involved reading the full-texts for congruence with eligibility criteria. At this level, articles were only retained if they included direct quotes from parent caregivers of ACWS, which were clearly delineated from quotes from other types of caregivers. This was aligned with principles of JBI (2014) as findings must be unequivocal (supported with illustrations that are beyond reasonable doubt attributable and not open to challenge), credible (findings have a clear association to the appropriate source), and supported by the data. Three reviewers (LY, LM, AV) completed this step and a second meeting was held to gain consensus on the studies to be included in the review.

Data Extraction

The primary reviewer (LY) extracted data from the chosen studies and created summary tables. Data included: a) study characteristics (i.e. author, year, title, country, purpose, design, data collection method, and data analysis method), b) parent caregiver characteristics (i.e. number of caregivers, age, sex, relationship with care recipient, marital status, education level, employment status, and years spent caregiving), c) ACWS (care recipient) characteristics (i.e. number of care recipients, age, sex, diagnosis, duration of illness, employment status, and housing type), and d) study outcomes (i.e. categories / themes and supporting quotes). These tables were reviewed and discussed in team meetings to ensure accuracy of the data extraction.

Data Synthesis

Study, caregiver, and care recipient characteristics were summarized and reported descriptively. Data, including all thematic constructions, descriptions, and supporting quotes found in the original articles were aggregated and analyzed using the Conventional Content Analysis Approach (Hsieh & Shannon, 2005). Specifically, two reviewers (LY and LM) read all quotes and made notes of first impressions and thoughts. Next, we highlighted text that captured key thoughts or concepts to derive initial codes (Morse & Field, 1995). Labels for these codes emerged from the text and were embedded into a preliminary coding scheme. We compared each label and code, and related codes were then aggregated into categories. Subcategories were used when appropriate. Finally, we embedded direct quotes from the original study participants into the synthesized findings. A quote was used to represent each category and subcategory. A third reviewer (AV) was consulted throughout the analysis process and aided in creating the final construction of the findings.

Rigour

This review is reported in accordance with the framework proposed by Tong and colleagues (2012): Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) (Tong, Flemming, McInnes, Oliver, & Craig, 2012). The ENTREQ statement consists of 21 items grouped in the following five domains: introduction, methods and methodology, literature search and selection, appraisal, and synthesis of findings. Adhering to these items enhanced the transparency of our research process.

Results

The search strategy produced a total of 2,321 citations. From these, we removed 750 duplicates and deemed 1,549 irrelevant after first-level screening. A total of 22 citations were subjected to second-level screening at which point a further 18 studies were excluded. The reasons for exclusion were: 1) unable to identify a parental quote for each theme or subtheme (n= 9), 2) diagnosis incorrect or unclear (n= 7), and 3) focus on care recipient experience rather than caregiver's experience (n= 2). Four studies met eligibility criteria and were included into the review from the database search and one additional study was found through the hand-search. A final set of five studies were included into the review (Figure 1).

Critical Appraisal

To assess the quality of the included studies, two reviewers (LY and LM) applied the Joanna Briggs Institute's Checklist for Qualitative Research (JBI, 2016). This critical appraisal tool consists of 10 questions that address the possibility of flaws in design, conduct, or analysis

(JBI, 2016). For each question, we allocated a rating of ‘yes’, ‘no’, ‘unclear’, or ‘not applicable’. Once completed, the two reviewers met with a third reviewer (AV) to discuss ratings and come to agreement on discrepancies. One point was awarded for each ‘yes’ and a total score was obtained for each study. Scores ranged from 7-9, with three studies receiving a score of 8. When considering whether participants’ voices were adequately represented, we made the decision to indicate “unclear” when the sources of quotes were vague (i.e. participant, parent, or informant). While quality assessment of included studies in Qualitative Evidence Syntheses is optional (Grant & Booth, 2009), we engaged in this step to comment on the state of science and make recommendations for future research on the topic (Table 3).

Study Characteristics

The included studies were conducted in Taiwan (n = 2), Canada (n = 1), Ireland (n = 1), and Sweden (n = 1). The study sample sizes ranged from six to 20 participants. All studies were qualitative and guided by a recognized qualitative methodology. Study designs included grounded theory (n=1), phenomenology (n=2), and descriptive qualitative approaches (n=2). Interviews were used to collect data in all cases and level of structure was described as either semi-structured (n = 4) or minimally structured (n = 1) (Table 4).

Caregiver Characteristics

Four of the five studies (Blomgren Mannerheim et al., 2016; Huang et al., 2009; McAuliffe et al., 2014; Yen et al., 2010) included both male and female parent caregiver participants and one study (Wiens & Daniluk, 2009) included male participants only. Females represented 55% of the total sample (n= 26 / 47) and the ages of the participants ranged from ‘late 40’s’ to 77 years. All participants identified as being either the mother or father of the care recipients. In three of the studies (Blomgren Mannerheim et al., 2016; McAuliffe et al., 2014;

Yen et al., 2010), the authors reported on the number of years spent caregiving; this ranged from one to 25 years (Table 5).

ACWS Characteristics

In total, there were 47 care recipients described and all studies included both male and female care recipients. Males represented 60% (n= 28) of the total sample. All care recipients had a diagnosis of schizophrenia, rather than schizoaffective disorder. The duration of illness was reported in two studies (Huang et al., 2009; Wiens & Daniluk, 2009) and length of diagnosis ranged from 3 to 26 years, with a mean duration of illness of 12 years. Age and type of housing was reported variably across studies (Table 6).

Themes and Categories Reported in Studies

In three studies (Huang et al., 2009; McAuliffe et al., 2014; Wiens & Daniluk, 2009), the authors reported their results using themes and subthemes and in two studies (Blomgren Mannerheim et al., 2016; Yen et al., 2010) the authors reported categories and subcategories. In all cases, the presentation of the findings (i.e. themes vs. categories) was congruent with the methodologies and data analysis strategies chosen. From the articles, we identified a total of 14 original themes supported by eight original subthemes, and three categories supported by eight original subcategories (n = 33 findings total).

After aggregating and comparing the original findings for similarities and differences, we identified five distinct categories: '*Access, Availability, and Appropriateness of Resources', 'Grieving Losses', 'Psychological Distress', 'Effects on Family',* and *'Framing the Experience'*. These categories are presented below with supporting subcategories, and include illustrative quotes from the original studies (Table 7).

Access, Availability, and Appropriateness of Resources

Issues of access, availability, and appropriateness of resources were identified in four articles (Blomgren Mannerheim et al., 2016; Huang et al., 2009; McAuliffe et al., 2014; Wiens & Daniluk, 2009). There were problems with missing resources and difficulties accessing resources that should have been readily available to them.

Parents predominantly spoke of deficits in resources available to meet their needs as caregivers for ACWS. Some parents reported a lack of overall support for family members, while others desired specific information, such as education and skills-based training to understand and manage symptoms of psychosis: “I appreciate the nurses who give us emotional support. But I need more help. For example, the skills to handle my daughter’s auditory hallucinations…” (Huang et. al, 2009).

Views of the availability and appropriateness of resources for ACWS were mixed. Some parents found the healthcare provided to their child to be comprehensive and complete:

> I feel that the healthcare has been good for xx. He has gotten a lot of good support from hospitals, rehabilitation, the employment service, and the social insurance company. I give [them] 100 points. But support for family members, nothing exists (Blomgren Mannerheim et al., 2016).

Other parents described a lack of psychosocial interventions: “I felt there was no real care… I felt… they were pumping the drugs. There was no real counselling” (McAuliffe et al., 2014) and a lack of physical resources, such as hospital beds, when their child was in crisis:

> They let him out of the hospital and he became psychotic again. I tried to take him back in and they said, ‘there are no beds.’ I said, ‘That’s your problem. He’s certified. You’re supposed to have a bed for him… (Wiens & Daniluk, 2009).

Ease of access to resources was also cited as problematic (McAuliffe et al., 2014; Wiens & Daniluk, 2009). In particular, parent caregivers identified difficulties navigating the healthcare system:

> There was no easy way to access anything…You know, it's fine to say that resources are there, but there was nothing that allowed us to feel like it was part of – not a right, but something is good to do – part of what we should be doing (Wiens & Daniluk, 2009).

This extended to gaining appropriate access to health care professionals: "No one ever came to me to talk to me about it. I asked the nurses questions… make an appointment to see the doctor…" (McAuliffe et al., 2014).

Grieving Losses

In all five studies, caregivers described experiencing a multitude of losses, which included loss related to the child (1, 2, 3, 4) and loss related to self (Blomgren Mannerheim et al., 2016; Huang et al., 2009; McAuliffe et al., 2014; Wiens & Daniluk, 2009)

Grieving losses related to child. Grieving losses related to child was identified in four articles and refers to the caregivers' senses of loss and grieving of the qualities and achievements that were representative of the child's past, or former self, as well as their aspirations previously held for their child's future.

Parents described the loss of their child's cognitive abilities and academic achievements: "… every time, when I recall how smart he was compared with now… I really feel heartbroken…" (Yen et al., 2010), and affective losses in relation to former expression:

> He was a beautiful baby – there was nothing wrong with him… now he's a sick man – that's the difference…I've a sick man now and I had a beautiful baby… as you can see

> from his photograph – he was a real bubbly little fellow… I'd give a million pounds to somebody to change it – It's desperate… (McAuliffe et al., 2014).

Parents also expressed loss when discussing their child's future. This was described as losing the belief that their child would have a great life or find success in the way they once imagined (Wiens & Daniluk, 2009): "So that image, the image of him being successful – of having a great life, is gone." (Wiens & Daniluk, 2009).

Grieving losses related to self. Losses related to self were described in four studies (Blomgren Mannerheim et al., 2016; Huang et al., 2009; McAuliffe et al., 2014; Wiens & Daniluk, 2009), and related to being unable to pursue their own personal goals and aspirations (past, present, and future) because of the demands of caregiving activities. Parents grieved social losses and described deep disappointment about not being able to experience the world as they anticipated: "My life was isolated. I feel sad about my life being like this…" (Huang et al., 2009). Another parent described personal losses in the following way:

> …lost a lot of my own life, things I'd like to do places I would like to go – I just can't do it… I'm 66 and not getting younger… I get upset about it at times… tormented. I get bitter about it in my own way (McAuliffe et al., 2014).

Further, parents described loss as all-encompassing; like a trade-off of their former life for the role of parenting ACWS:

> I really feel the responsibility to care for our son is mine. So I still give up everything to have the responsibility, but I'm quite upset about the fact that I'm getting older and I don't know, I just won't be able to do what I wanted to do (Wiens & Daniluk, 2009).

Changes to their day-to-day routines and the inability to engage as desired in activities were also described:

> His illness has also limited my daily freedom of action as well as weekends such as Saturday or Sunday, since half of the week xx and I eat dinner together. My social life is also limited because I get fewer free nights off to meet people (Blomgren Mannerheim et al., 2016).

Parents spoke about future anticipated losses, especially related to loss of an enjoyable retirement. "It's not our idea of something as a retirement gift" (Wiens & Daniluk, 2009). Participants explained how a diagnosis of schizophrenia for their child was the greatest loss ever experienced: "The death of my father, the death of my mother, other deaths I've experienced – I've never felt like I did when my child was diagnosed with schizophrenia" (Wiens & Daniluk, 2009).

Psychological Distress

Psychological distress was evident in all five studies and was described as the psychological turmoil experienced by parent caregivers throughout their child's illness trajectory. Most often, this distress was described in terms of guilt about the past (Huang et al., 2009; Wiens & Daniluk, 2009; Yen et al., 2010), devastation regarding their child's illness and its effects (all studies), fear (Huang et al., 2009; McAuliffe et al, 2014; Wiens & Daniluk, 2009), and worries about an uncertain future (Blomgren Mannerheim et al., 2016; Huang et al., 2009; McAuliffe et al, 2014; Wiens & Daniluk, 2009).

Guilt. Guilt (Huang et al., 2009; Wiens & Daniluk, 2009; Yen et al., 2010) was predominantly related to self-blame for the child developing schizophrenia: "I felt so guilty when my son asked me why I gave birth to him and why he got this illness. I always have a deep feeling of self-blame about my son's illness" (Huang et al., 2009). This self-blame was evident when parents spoke of the hereditary component of the illness:

> The doctor told me that genetics is one factor of mental illness. My husband and I kept asking, how come we have passed this bad gene? Are we the persons who should be blamed for our child's illness? The more I think, the more sorry I feel for him. Every time, when he goes into a temper, I tell myself… be patient…I gave birth to him (Yen et al., 2010).

Parents also described feeling guilty about failing to recognize early signs and symptoms of the illness: "We always said we should have realized it sooner" (Wiens & Daniluk, 2009). Parents appeared to feel great responsibility over recognizing the prodromal symptoms of schizophrenia:

> I should be responsible for her illness. I thought I was not a good mother because I did not take good care of her. If I had discovered her problem earlier, she might not have become mentally ill. Now, it's too late… all I can do was to do my best to provide good care (Yen et al., 2010).

Devastation. Devastation was evident in all five studies and was described across the illness trajectory in terms of overwhelming sadness (Huang et al., 2009; Wiens & Daniluk, 2009; Yen et al., 2010), and feelings of hopelessness (Wiens & Daniluk, 2009), powerlessness (Blomgren Mannerheim et al., 2016; Wiens & Daniluk, 2009), and desperation (McAuliffe et al., 2014). There was a temporal dimension to devastation: devastation with diagnosis, devastation with exacerbation of symptoms, and ongoing devastation.

Devastation felt upon learning of their child's diagnosis was described as being especially difficult and life changing:

> When he said that our daughter has schizophrenia, I just felt like the bottom had fallen out of my world and I felt very sad for my daughter. I felt like it was a death sentence for

> her and I was mute. I have to say I felt hopeless at that time… the other word is powerless (Wiens & Daniluk, 2009).

During times of symptom exacerbation, parents described the devastation of having to bring their ACWS to hospital against their will when they could no longer manage at home:

> We brought him back to the hospital – forced him back. It was just horrible – and he was crying and angry and it was devastating. It was another major, major blow to us… Then he didn't want to see us – was holding it against us (Wiens & Daniluk, 2009).

As parents navigated the trajectory of their child's illness, devastation continued to be a part of their experience: "I remember grabbing on to him and just saying, you know, that I love him and actually crying with him. And it was really weird because I don't do that… but I was just like – devastated" (Wiens & Daniluk, 2009).

Fear. Fear was described in three studies (Huang et al., 2009; McAuliffe et al., 2014; Wiens & Daniluk, 2009) and was expressed as generalized and ongoing. Parents feared unknown aspects of the illness: "When he wasn't well in the beginning – it was an awful worry that he could do anything… be afraid to watch him every single minute just in case" (McAuliffe et al., 2014). Parents also feared that their child might resist care when needed: "Sometimes when we went to the hospital we have spent up to five hours in emergency to get him hospitalized. And we're afraid our son will bolt on us" (Wiens & Daniluk, 2009). Finally, parents were afraid that their child might commit suicide because of the overwhelming nature of their symptoms: "I fear my daughter will commit suicide as hallucinatory voices often tell her to kill herself…" (Huang et al., 2009).

Worries about an uncertain future. Worry related to both the realization that schizophrenia is an unpredictable illness (Blomgren Mannerheim et al., 2016; Wiens & Daniluk, 2009), as well as worry about who would care for their child once they were no longer capable (Huang et al., 2009; McAuliffe et al., 2014). Parents worried about what would happen to their child once they died: “I always worry about my son’s future. Who will take care of him when I die? You know his illness can never be cured” (Huang et al., 2009). Some parents had concerns that their child would not be able to go on without them: “But I don’t know can he look farther than just now and what would become of him, if I wasn’t looking after him… He wouldn’t be able to carry on, on his own” (McAuliffe et al., 2014). Alternatively, while other parents couldn’t be sure what the future would hold for their child, they seemed more readily accepting of their child’s ability to be independent:

> He’d be thinking about the future himself – he’d like to get married – but sure he never will… he don’t go anywhere like… I suppose I know he’d be on his own some fine day but then again as I said – they (siblings) are near him… He’d manage away (McAuliffe et al., 2014).

Effects on family

Caring for ACWS had significant effects on the families. This was described in terms of family relationships (Blomgren Mannerheim et al., 2016; Huang et al., 2009; McAuliffe et al., 2014; Wiens & Daniluk, 2009) and increased responsibilities (Blomgren Mannerheim et al., 2016; McAuliffe et al., 2014; Wiens & Daniluk, 2009; Yen et al., 2010).

Effects on family relationships. Family conflict occurred as a result of a lack of understanding of illness symptoms, such as beliefs that the ACWS was lazy: “His brothers usually argue with him. Sometimes they fight with each other because he does not have a job and just sits around at home and gets looked after. They think he is a lazy, useless man” (Huang et al., 2009). If one parent experienced negative emotions and poor coping skills these appeared to have a ripple effect on other family members, creating greater conflict and tension.

> When (daughter) got ill, my husband became very hateful toward me and also put the hatred on my children. I’ve never felt so hated; it was like his aggressions went over to my daughter and she kind of threw darts at me. I’ve never felt so bad, it felt horrible and unfair (Blomgren Mannerheim et al., 2016).

The effects of caregiving on the marital relationship were mixed. From a positive perspective, some participants reported that their marriage was strengthened due to overcoming obstacles together: “I think, if anything, all of this experience strengthened our marriage – brought us closer together. We certainly have a common problem and we need to work together to deal with it” (Wiens & Daniluk, 2009). Others indicated that because of limited quality time spent together as spouses, their marriages suffered:

> It’s very bad for a marriage – for a mother to have so much hardship so much worry because you have no time to spend with your husband – only that my husband is so understanding – all I go through – there’s nothing I can do about it… under strain all the time – God almighty I couldn’t sit down at night with my husband – we don’t have time (McAuliffe et al., 2014).

Increased responsibility. Increased responsibility for caregiving and its effect on the family unit was described by parent caregivers in four studies (Blomgren Mannerheim et al., 2016; McAuliffe et al., 2014; Wiens & Daniluk, 2009; Yen et al., 2010). This outcome was articulated as a value that was embedded in both family dynamics and cultural expectations. The sense of responsibility that caregivers described related to the belief that one should do all that they can to ensure a good life for their ACWS: “I would probably walk through a wall for him…

that’s just sort of the way I view how important he is in my life” (Wiens & Daniluk, 2009). The responsibility was embedded in parents’ beliefs regarding parental obligation: “Our role is still to be the parent and do the best for him” (Wiens & Daniluk, 2009). Further, ensuring the best possible quality of life for their ACWS despite the limitations associated with schizophrenia was paramount: “We have to make him have as good a life as possible… that’s all we can do.” (Wiens & Daniluk, 2009).

In one study, this sense of parental responsibility was strongly influenced by cultural beliefs and public perception of the family:

> He is my child, I have the responsibility to take care of him. We are family… that is what family should do… You know… We are Taiwanese… Taiwanese emphasise family ethics and values. If we give him up, the public will blame us and we cannot have peace of mind (Yen et al., 2010).

Furthermore, accepting added responsibility was related, in two studies, to religious or spiritual beliefs:

> Renming [accepting misfortunes as decreed by fate]… otherwise… what should I do? I am the person who believes in fate… It is my fate. Who would like to take care of him (son) for me? No one… I cannot abandon my son… and cannot change the reality… My life is destined. Accept the fate rather than hate my life (Yen et al., 2010).

Framing the experience

Participants described that appraising or “framing” their caregiving experiences in positive or meaningful ways helped them cope with their role. Framing the experience occurred through consciously choosing to focus on positive thoughts (subcategory: Positive Thoughts) (Blomgren Mannerheim et al., 2016; Huang et al., 2009; McAuliffe et al., 2014; Wiens &

Daniluk, 2009), believing and succumbing to a higher power (subcategory: Religious or Spiritual Beliefs) (Huang et al., 2009; McAuliffe et al., 2014; Yen et al., 2010), and engaging in personal growth (subcategory: Personal Growth) (Blomgren Mannerheim et al., 2016; McAuliffe et al., 2014; Wiens & Daniluk, 2009; Yen et al., 2010).

Positive thoughts. Positive thoughts were described in four studies (Blomgren Mannerheim et al., 2016; Huang et al., 2009; McAuliffe et al., 2014; Wiens & Daniluk, 2009) and referred to parent caregivers consciously choosing a state of mind or gaining knowledge that shaped their perspective and helped them to cope with their caregiver role. The participants indicated how adopting and maintaining a positive attitude was an essential ingredient in coping within their role: "I tried to keep thinking positively and resolve problems… I obtained knowledge from the doctor and the community nurse" (Huang et al., 2009). Parent caregivers also explained how providing caregiving resulted in such a busy schedule that they did not have time to reflect on their emotions:

> Well you know – you live from day to day – I'm so busy in my life – I haven't time to sit down and cry… I'd get emotional maybe off and on and I'd say well – this is terrible – What can I do… You just have to move on… You get used to it (McAuliffe et al., 2014).

Making the conscious decision to prioritize balance helped caregivers to maintain their role:

> I've got my own home that I can go to, and I can meet my friends at my place. I even try to have some fun stuff so I can get some balance. I have done this consciously to feel good and I work with it consciously (Blomgren Mannerheim et al., 2016).

Taking a break from their caregiving responsibilities for reflection was helpful for gaining this balance and perspective: "… I said what I'll do is go away for a few days … come back with a fresh view… weigh the situation… which is what I did – I came to… the cottage – spent four days… thinking" (McAuliffe et al., 2014).

Religious or spiritual beliefs. Religious or spiritual beliefs were spoken about in three studies (Huang et al., 2009; McAuliffe et al., 2014; Yen et al., 2010). These beliefs and practices framed their experiences, both in terms of understanding why and how they came into this role, as well as providing strength and courage to continue. Some parent caregivers explained that they fell into this role because of karma or as punishment for behaviour in a past life:

> Why don't other people have to suffer the same thing (having a child with schizophrenia) as me. I always tell myself I must owe my son in my past life. So, I need to pay back in this life. When I repay my debt, then, my karma will disappear (Huang et al., 2009).

Similarly, some participants explained how their gods aligned this role to foster their caring attributes or patience: "… it's a test and a practice of my life tasks… the gods might have some purpose to assign me to be a caregiver… I am not patient or caring enough… so the gods want to chasten my patience." (Yen et al., 2010). Religious ritual and the power of prayer, both within and outside of temples or churches, was also cited as being helpful to maintain one's role as caregiver: "I depend on him (God) for everything – he got me through all this… I am a believer… mass is very helpful because it was a nightmare you know" (McAuliffe et al., 2014).

Personal growth. Personal growth was identified in four studies (Blomgren Mannerheim et al., 2016; McAuliffe et al., 2014; Wiens & Daniluk, 2009; Yen et al., 2010) and was described as both a motivating factor for caregiving and an outcome of caregiving. Personal growth involved the caregiver's evolution of character and their enhanced ability to cope with their caregiver experiences. Engaging in the role of caregiver led to establishing a stronger sense of strength, ability for change, developing greater compassion, and becoming less judgemental.

Caregivers' experienced personal growth in response to negative circumstances, from which learned to cope and manage life's ups and downs:

> I have a history of difficult things happening in life; therefore, I feel proud that I have managed it – now I go and sing and make sure that I get out and away… dance and try to do the things that I'm good at and that's fun, to get some air under my wings. I've learned and I feel proud over this (Blomgren Mannerheim et al., 2016).

The experience of having ACWS led parents to feel stronger: "I just feel like – I have to compliment myself and say I'm a strong person – because it just makes me realize that – when I talk to other parents who, when faced with this situation, couldn't do it" (Wiens & Daniluk, 2009). They recognized that this strength came from seeing their child through challenged of schizophrenia:

> I think it's a real eye opener to me to see how I can change… What I do know is that I'm willing to do it. It's a fight between who I am and what I need to do for this child, right? (Wiens & Daniluk, 2009).

Discussion

This qualitative evidence synthesis highlights the caregiving experiences of parents of ACWS. Across the studies, findings revealed the psychological distress apparent in their lives, their experiences with loss, and the ways in which they framed their realities.

Psychological Distress

Psychological distress was described in all of the included studies. This finding is consistent with quantitative studies reporting high levels of psychological distress experienced by caregivers of a family member with schizophrenia (Hanzawa et al., 2013; Ong, Ibrahim, & Wahab, 2016). Psychological distress is largely influenced by the subjective experience of burden and is shown to be mediated by severity of psychopathology of the care recipient, time spent in caregiving activities, and coping strategies used (Kate, Grover, Kulhara, & Nehra, 2013). Unfortunately, parent caregivers for ACWS experience poor quality of life (Grover, Pradyumna, & Chakrabarti, 2015), receive inadequate support from psychiatric services (Shah, Sultan, Faisal, & Irfan, 2013), and are known to be at high risk for psychiatric comorbidities, such as anxiety, depression, or post-traumatic stress (Hanzawa et al., 2013; Schulz, Hebert, & Boerner, 2008). While support groups, education groups, counselling, and respite services are important approaches to supporting caregivers' psychological health and well-being (Dangdomyouth, Stern, Oumtanee, & Yunibhand, 2008), parents in the studies reviewed here described difficulties identifying and navigating the systems housing these resources (Blomgren Mannerheim, Hellström Muhli, & Siouta, 2016; McAuliffe, O'Connor, & Meagher, 2014; Wiens & Daniluk, 2009).

Improving resource accessibility can effectively improve caregiver experience and reduce stress (Hanzawa et al., 2013). With appropriate training and knowledge of local resources, nurses can not only recommend support services, but also serve as system navigators for families. Furthermore, nurses can work with parents to help them use adaptive coping strategies to ease their distress, prevent further deterioration, and respond more positively to their environment (Ong, Ibrahim, & Wahab, 2016; Tsai, 2003).

Loss

The parent caregivers in this review experienced a number of losses, including losses related to their child and personal losses. This finding is consistent with literature exploring the caregiving experiences in the context of schizophrenia published before our review timeframe (Ferriter & Huband, 2003; Tuck, du Mont, Evans, & Shupe, 1997). In some cases, the parents equated loss related to schizophrenia to loss related to death. The similarities in these experiences included emotional turmoil and the need to make sense of things and create new meanings (Christ, Bonanno, Malkinson, & Rubin, 2003). Loss in the context of death is permanent, whereas parent caregivers experiencing loss in the context of schizophrenia have multiple unpredictable and non-linear losses, which occur throughout the illness trajectory. Parents described losing their child's 'normal life', academic achievements, vocational aspirations, and personhood because of cognitive, personality, and affective changes.

These losses cause tremendous distress and when preservation of family relationships is not prioritized, family support can wean over time, leaving ill persons isolated and alone (Avasthi, 2010). Very little research exists to explain this attrition of family support, yet Glynn and colleagues (2006) found, in a group of schizophrenia outpatients, that 71% under age 45 reported their parents to be their most supportive relatives, whereas only 32% over the age of 45 reported the same (Glynn, Cohen, Dixon, & Niv, 2006). Based on our practice experiences, we have similarly noted that the number of family members present and involved in care decreases over time, which from an anecdotal observation appears to be associated with exacerbations of illness symptoms. Clearly it is important to understand why this attrition in caregivers occurs, and research is needed to explore the associated factors.

For persons with schizophrenia, family support is imperative, and research shows that poor family support is a risk factor for exacerbation of symptoms and illness relapse while adequate family support is a protective factor against illness (Glynn, Cohen, Dixon, & Niv, 2006; Sariah, Outwater, & Malima, 2014). Currently, there are no specific guidelines or models to explain or predict loss, and we were unable to locate any interventions designed to support parents experiencing loss related to schizophrenia. Grief interventions for parents following death of a child (Endo, Yonemoto, & Yamada, 2015) might offer some insight into this phenomenon, though more research is needed to fully explore the ways in which loss is experienced in the context of schizophrenia. Our findings suggest that at minimum, nurses and other healthcare practitioners should engage in frank conversations, early in the illness trajectory, about recovery expectations and pre-planning for loss and relapse and that clinical support should be provided to caregivers in order to help them cope with losses.

Framing the Experience

The findings of this review indicated that parent caregivers of ACWS can frame their experiences of caregiving and being the parent of an ACWS in adaptive ways to support a more meaningful and positive perspective. This is consistent with literature supporting the idea that cognitive appraisal plays a significant role in how individuals respond and adapt to situations (Lazarus & Folkman, 1984). Examining how caregivers adapt is as important as studying maladaptation to stress in the context of schizophrenia (Avasthi, 2010; Awad & Voruganti, 2008; Bauer, Koepke, Sterzinger, & Spiessl, 2012; Hsiao & Tsai, 2014), and evidence supports the use of coping processes that focus on positive psychological states when experiencing intense distress (Folkman, 1997; Cohen, Colantonio, & Vernich, 2002; Zarit, 2012). Counselling approaches, such as Cognitive Behavioural Therapy (CBT) (Beck, Rector, Stolar, & Grant, 2008), are often used with caregivers (generally) to help them frame their experiences more positively and ultimately cope better with their role (Alberti, 2016). While promising, more research is needed to examine the effectiveness of CBT and other therapeutic interventions for caregivers of persons with schizophrenia (Alberti, 2016).

Considerations for Transferability of Findings

It is important to recognize the influence of culture and sex and gender on the transferability of these findings. Two of the five studies included were conducted in Taiwan (Yen, Teng, Huang, Ma, Lee, & Tseng, 2010; Huang, Hung, Sun, Lin, & Chen, 2009), where religion, spirituality, and karma perpetuated descriptions of these caregivers' realities. Karma relates to the sum of a person's actions in this and previous states of existence and how this influences fate in future existence (Wu, 1992). The belief that one's circumstances are determined by fate emphasizes a lack of control, which differs between Asian and North American or European Cultures. In Asian cultures, psychological and moral explanations of mental illness are common, whereas biological and genetic explanations of mental illness are more readily accepted by North American and European caregivers (Wu, 1992). In multicultural countries and countries that experience immigration, nurses provide care for people of vast cultural inheritance. Findings from this review provide some insight into the particularities of caregiver experiences across cultures, though the number of papers representing each are small. Further qualitative exploration of caregiver experiences within homogenous samples will better our understanding of cultural variations.

The influence of sex and gender on experience should also be considered when interpreting the findings of this synthesis. In the included studies, females represented only half (55%) of the total sample of parent caregivers. One study was specific to fathers' experiences (Wiens & Daniluk, 2009), and even when calculating proportions of males and females with the exclusion of this study, female participant representation was still far below estimated norms. In the United States, approximately 82% of family caregivers are female and 90% of schizophrenia caregivers are mothers of ACWS (Awad & Voruganti, 2008). Gendered research on caregiving highlights the differences between men and women in their enactment of this role, and differences in perceived needs may be rooted in gender. Researchers should consider exploring the differences in experiences between mothers and fathers as influenced by gender.

Limitations

There are limitations to consider when interpreting the findings of this review. First, it is possible that the search strategy failed to identify all pertinent literature. To minimize this threat, we designed and conducted the search with the assistance of two library scientists with expertise in systematic review methodologies. Surprisingly, we found one study (Blomgren Mannerheim, Hellström Muhli, & Siouta, 2016) by happenstance, which was not identified by our search strategy. In light of this discovery, an additional meeting with a library scientist revealed that the article did not have assigned MESH headings and was only available via an external link on PubMed Central, thus making it non-retrievable. It is possible that other pertinent studies with similar indexing issues were also missed. Second, we chose a 10-year time frame, which is typical of reviews (Helfand & Balshem, 2010); however, earlier studies might have been relevant to the topic. Third, inclusion criteria specified that parent caregiver experiences needed to be supported by participant quotes, clearly reflective of only parent participants, and specific to ACWS. As such, studies with quotes that did not specifically identify the source as parents of ACWS or studies lacking the specific diagnoses of schizophrenia or schizoaffective disorder (i.e. severe and persistent mental illness, psychosis, first-episode psychosis), were eliminated. It is possible that relevant experiences were embedded within these other study findings. Fourth, when one synthesizes aggregated qualitative data from multiple sources, there is a possibility for bias or misrepresentation of the original experience because data are garnered from secondary sources. Furthermore, aggregated findings stem from studies using varied methodologies or situated within different paradigmatic views. This is a risk for all meta-synthesis studies (Sandelowski, Docherty, & Emden, 1997; Walsh & Downe, 2005).

Conclusion

The aim of this review was to synthesize recent qualitative literature that explored the experiences of parent caregivers for ACWS. Experiences of loss were prevalent and parent caregivers grieve losses related to their child and themselves. Parent caregivers need help navigating available services and support for their own mental and physical health needs. Importantly, parent caregivers were able to frame their experiences in ways that were helpful for their coping and maintaining their caregiving role. In practice, there is a need to improve accessibility and understanding of available resources in order to reduce psychological distress of parent caregivers. From a research perspective, factors influencing parents' abilities to stay engaged in caregiving warrant further exploration. Developing guidelines or models to explain and/or predict loss in schizophrenia are also needed, as are specific interventions designed to support parent caregivers in their roles.

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Table 1
Eligibility Criteria

Inclusion	Exclusion
Phenomena of Interest – The caregiving experience	
Population – Parents (mother, father, single parent, foster, grandparent, or adoptive parent – anyone acting in parental role) of an adult child (18+yrs) with a diagnosis of schizophrenia or schizoaffective disorder.	Other caregivers, parents of youth or children, parents of an adult child with any other mental illness including substance induced psychosis, first episode psychosis, delusional disorder, or psychosis NOS.
	Persons with primary or secondary diagnosis of dementia
Qualitative or mixed method s studies with a standalone qualitative piece.	Quantitative Studies only
Articles that include other caregivers but can distinguish a minimum of one parent quote supporting each theme or category	Articles without direct quotes
Articles published in English and within the last 10 years (2006 – November 2016).	Articles published in any other language and outside of the last 10 years or not available online.
Full-text peer-reviewed studies	Unpublished or grey literature, abstracts, theses, dissertations, books, and conference summaries.
Context – worldwide, any culture, race, or gender. Caregiving may occur in the community or while person is within hospital.	

Table 2

Example Search Strategy

	MEDLINE	
1	Exp “schizophrenia spectrum and other psychotic disorders”/	150,346
2	schiz*.ti. or schiz*.ab.	139483
3	psycho*.ti. or psycho*.ab.	555205
4	1 or 2 or 3	691074
5	Caregivers/	31144
6	(caregiv* or carer* or "care giver*").ti. or (caregiv* or carer* or "care giver*").ab.	64493
7	parents/ or fathers/ or mothers/ or single parent/	99954
8	(parent* or mother* or father* or "single parent*").ti. or (parent* or mother* or father* or "single parent*").ab.	558670
9	5 or 6 or 7 or 8	640415
10	4 and 9	55291
11	limit 10 to (English language and full text and yr="2006 - 2016")	4640
12	(qualitative* or interview* or "focus group*" or narrative*).ti. or (qualitative* or interview* or "focus group*" or narrative*).ab.	506359
13	11 and 12	865

Table 3

Joanna Briggs Institute – Checklist for Qualitative Research

Criteria	Huang, Hung, Sun, Lin, & Chen (2009)	Wiens & Daniluk (2009)	Yen, Teng, Huang, Ma, Lee, & Tseng (2010)	McAuliffe, O'Connor, &Meagher (2014)	Blomgren Mannerheim, Hellström Muhli, & Siouta (2016)
1. Is there congruity between the stated philosophical perspective and the research methodology?	Yes	Yes	Yes	Yes	Yes
2. Is there congruity between the research methodology and the research question or objectives?	Yes	Yes	Yes	Yes	Yes
3. Is there congruity between the research methodology and the methods used to collect data?	Yes	Yes	Yes	Yes	Yes
4. Is there congruity between the research methodology and the representation and analysis of data?	Yes	Yes	Yes	Yes	Yes
5. Is there congruity between the research methodology and the interpretation of results?	Yes	Yes	Yes	Yes	Yes
6. Is there a statement locating the researcher culturally or theoretically?	Unclear	Yes	Unclear	Yes	Yes
7. Is the influence of the researcher on the	Yes	Yes	No	No	Yes

research, and vice-versa, addressed?					
8. Are participants, and their voices, adequately represented?	Yes	Unclear	Unclear	Unclear	Unclear
9. Is the research ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body?	Yes	No	Yes	Yes	Unclear
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Yes	Yes	Yes	Yes	Yes
Total	9	8	7	8	8

Table 4
Study Characteristics

Author (Year)	Country	Title	Purpose	Design	Data Collection Method	Data Analysis Method
Huang, Hung, Sun, Lin, & Chen (2009)	Taiwan	The experiences of carers in Taiwanese culture who have long-term schizophrenia in their families: a phenomenological study	To explore the experiences of carers who live with someone with long-term schizophrenia, within the cultural context of Taiwan	Descriptive phenomenological approach	Semi-structured interviews	Colaizzi's (1978) seven-step method
Wiens & Daniluk (2009)	Canada	Love, loss, and learning: The experiences of fathers who have children diagnosed with schizophrenia	To give voice to fathers of young ACWS within the past 10 years	Phenomenological approach	Minimally structured data collection interview	Seven steps of phenomenological analysis outlined by Colaizzi (1978)
Yen, Teng, Huang, Ma, Lee, & Tseng (2010)	Taiwan	A theory of meaning of caregiving for parents of mentally ill children in Taiwan, a qualitative study	To generate a theory of meaning of care-giving for parents of mentally ill children in Taiwan	Grounded Theory	Semi-structured interviews	Constant comparative method
McAuliffe, O'Connor, &Meagher (2014)	Ireland	Parents' experience of living with and caring for an adult son or daughter with schizophrenia at home in Ireland: a qualitative study	To explore the experience of parents living with and caring for their a ACWS	Descriptive qualitative design	Semi-structured, interviews	Eclectic approach described by Creswell (2002)
Blomgren Mannerheim, Hellström	Sweden	Parents' experiences of caring responsibility for their adult child with	To systematically describe and analyze the experiences of parents'	Descriptive Qualitative	Semi-structured interviews	A mixed hermeneutic deductive and

Muhli,& Siouta (2016)	schizophrenia	informal care responsibility		inductive method

Table 5

Caregiver Characteristics

Author (Year)	N	Age	Relationship to Adult Child with Schizophrenia	Marital Status	Education Level	Years spent caregiving
Huang, Hung, Sun, Lin, & Chen (2009)	7	67, 59, 75, 58, 62, 50, 66	4 Mothers 3 Fathers	5 Married 2 Widow	3 None 2 Primary 2 Junior	
Wiens & Daniluk (2009)	6	4 were in their late 40s and 50s, 1 in early 60s, 1 in early 70s.	6 Fathers			
Yen, Teng, Huang, Ma, Lee, & Tseng (2010)	20	48 – 65 years	12 Mothers 8 Fathers		Ranged from primary to high school.	Range 1 – 12 yrs. Average: 1-3 yrs (N = 11)
McAuliffe, O’Connor, &Meagher (2014)	6	60 – 77 (mean not provided though, 69, 60, 77, 66, 76, 66)	5 Mothers 1 Father	3 Married 3 Widow		Range: 6 – 25 years. Average: 17 yrs (25, 19, 23, 8, 22, 6).
Blomgren Mannerheim, Hellström Muhli,& Siouta (2016)	8	52 – 63 (58, 58, 56, 52, 57, 63, 59, 59)	5 Mothers 3 Fathers	Married (4) Single Parent (4)		5 years minimum

Table 6

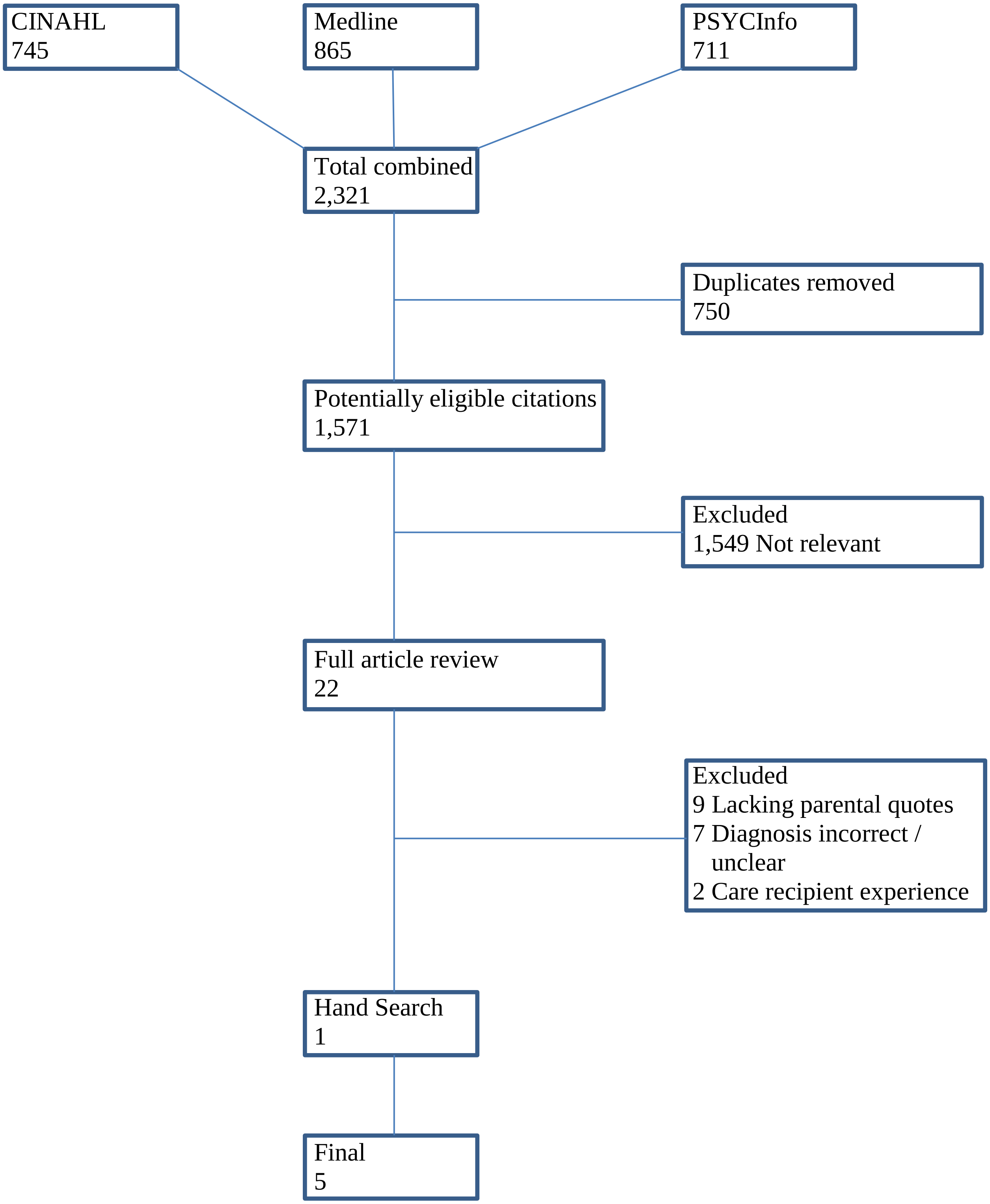
Care Recipient Characteristics

Author (Year)	N	Age	Sex	Diagnosis	Duration of Illness	Housing Type / Live with Parent
Huang, Hung, Sun, Lin, & Chen (2009)	7	32, 31, 24, 38, 23, 38, 50	2 F 5 M	Schizophrenia	16, 6, 3, 18, 6, 19, 18	Inclusion criteria they had lived with the person for at least 1 year
Wiens & Daniluk (2009)	6	18 – 31 years	1 F 5 M	Schizophrenia	4 diagnosed approximately 4 yrs, 2 had been diagnosed 8 yrs	5 living semi-independently out of parental home; 1 living at home
Yen, Teng, Huang, Ma, Lee, & Tseng (2010)	20	25.7 (SD 4.73).	12 F 8 M	Schizophrenia		
McAuliffe, O’Connor, &Meagher (2014)	6	45, 36, 40, 27, 38, 37	2 F 4 M	Schizophrenia		Inclusion criteria all live with parents for at least two years
Blomgren Mannerheim, Hellström Muhli,& Siouta (2016)	8	22 – 31 (27, 25, 40, 23, 22, 31, 30, 27)	2 F 6 M	Schizophrenia	Minimum of 5 years as per parents informal caregiving provided minimum 5 years	

Table 7
Categories and Subcategories

Category	Subcategory
Access, Availability, Appropriateness of Resources	*(No sub-category)*
Grieving Losses	Grieving Losses Related to Child Grieving Losses Related to Self
Psychological Distress	Guilt Devastation Fear Worries about an Uncertain Future
Effects on Family	Effects on Family Relationships Increased Responsibility
Framing the Experience	Positive Thoughts Religious or Spiritual Beliefs Personal Growth

Figure 1. Search Tree Diagram



Chapter Four

Exploring the Experiences of Parent Caregivers in Schizophrenia:

A Qualitative Study

This chapter is an unpublished manuscript formatted for submission to an academic peer-reviewed psychiatric nursing journal

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Abstract

Parent caregivers support the health, well-being, and recovery goals of their adult children with schizophrenia. As a result, parent caregivers are required to modify many elements of their lives and are susceptible to experiencing psychological distress. Some research exists that explores caregiving in the context of mental illness and schizophrenia specifically. Less is known about how parents enact and experience this role when caregiving for an adult child. The purpose of this study was to explore the caregiving experiences of parents caring for an adult child with schizophrenia. 12 English-speaking parent caregivers for adult children with schizophrenia completed semi-structured interviews. Data were analyzed according to conventional content analysis. Findings included: "Uncertainty and Change" (Couldn't put a finger on it; Things I do; Things I thought I would never have to do; How do I do what I need to do?); and "Caregiving: Effects on my life" (The bad; The good). Parent caregivers described difficulties accessing and navigating mental health resources, emotionally challenging instances of interacting with police, and tremendous psychological distress. Effective strategies are needed to help parent caregivers anticipate and cope with loss and gain access to timely and appropriate care.

Keywords: adult children, caregivers, parents, qualitative research, schizophrenia.

Background

Schizophrenia is a chronic mental disorder with an unpredictable illness trajectory and afflicted individuals fluctuate between acute, stabilization, and chronic phases (American Psychiatric Association, 2013). Initiating, maintaining, and optimizing treatment across the illness trajectory is a complicated process that presents a number of challenges for family caregivers and often parents assumed this role for their adult children with schizophrenia (ACWS). With current mandates in mental health embracing community care within a recovery-orientation (Mental Health Commission of Canada, 2012), parent caregivers play a leading role in supporting the health, well-being, and recovery goals of their ACWS. These family members might be required to provide social, physical, or medical care. From a social perspective, this includes emotional support in the form of care, empathy, and love, among others (House, 1981). Physical care might include cooking, cleaning, or attending to hygiene needs (Small, Harrison, & Newell, 2010). Finally, medical care might include medication administration or wound care.

Given the complex needs of persons with schizophrenia, parent caregivers face a number of challenges. At the onset of the illness, indiscriminate symptoms make early identification of schizophrenia difficult. This leads to delayed treatment and, at times, long periods of untreated psychosis (Yung & Barnaby, 2013). Not only does untreated psychosis result in increased symptom severity and decreased social and global functioning (Penttilä, Jääskeläinen, Hirvonen, Isohanni, & Miettunen, 2014), parent caregivers experience tremendous guilt related to not knowing how to help during this time (Wiens & Daniluk, 2009). Furthermore, parent caregivers cite problems with accessing available and appropriate mental health services (Wainwright, Glentworth, Haddock, Bentley, & Lobban, 2015; Jack-Ide, Uys, & Middleton, 2013; Wiens & Daniluk, 2009). When persons with schizophrenia are unable to receive required care, they are at risk for hospitalization, experiencing difficult and frightening symptoms, and suicide (Higashi, Medic, Littlewood, Diez, Granstrom, & De Hert, 2013).

Parents assuming a caregiver role must learn to navigate illness and services-related challenges, while enduring financial and social costs, family conflict, and poor personal physical and mental health outcomes (Awad & Voruganti, 2008). Anxiety, depression, fear, and anger are commonly reported emotional consequences, and physical manifestations include headaches, stomach pains, constant tiredness, and insomnia (Small, Harrison, & Newell, 2010). Caregivers report an overall reduction in their quality of life and increased distress because of their role (Quah, 2014; Sapouna et al., 2013).

Schizophrenia is a debilitating mental illness that significantly affects not only the individual suffering from the illness, but also the entire family (Awad & Voruganti, 2008; Kate, Grover, Kulhara, & Nehra, 2014). Caregivers for ACWS face unique challenges and considerations, such as the intersection of mental health care and mental health law, issues of competence and insight, and difficult symptoms such as paranoia. When it comes to exploring caregiving and schizophrenia in the literature, the vast majority of research focuses on caregiver burden, which is a significant component of the caregiving experience (Awad & Voruganti, 2008; Caqueo-Urízar, Miranda-Castillo, Giráldez, Maturana, Ramírez Pérez, & Mascayano Tapia, 2014; Chien, Chan, & Morrissey, 2007; Small, Harrison, & Newell, 2010). Caregiving burden can be defined as the negative emotional, psychological, physical, and economic impact of caring, as well as distressing notions such as shame, self-blame, and feelings of guilt (Awad & Voruganti, 2008).

Understanding the experiences of parent caregivers is important and researchers identify a deficit of work in this area (Hsiao & Tsai, 2014). While researchers have examined family experiences, few studies have explored the experiences of *parents* specifically (Wiens & Daniluk, 2009; Yen, Teng, Huang, Ma, Lee, & Tseng, 2010). As such, the purpose of this study was to explore the caregiving experiences of parents of ACWS. Nurses equipped with this understanding are better able to recognize the importance of assessing the health and well-being of family members and integrating their needs into the plan of care.

Research Question

How do parents in a large urban Canadian city experience their role as caregivers for ACWS?

Methods

Design

This Interpretive Description (ID) (Thorne, 2008) qualitative study explored how parents experience their role as caregivers for ACWS. ID creates ways of understanding a phenomenon while generating knowledge relevant for clinical practice (Thorne, Reimer Kirkham, O'Flynn-Magee, 2004). The methodology is situated within the constructivist paradigm (Lincoln & Guba, 1985), which assumes the existence of multiple realties. By using ID, we were able to reveal themes, relationships, and patterns within the experience of being a parent caregiver for an adult child with schizophrenia, while also accounting for individual variations. The product of this approach does not constitute a new truth, but rather a 'tentative truth claim' (Thorne, 2008) about what is common amongst the parent caregiver participants.

Situating the Research Team

The research team had expertise in qualitative research and psychiatric and mental health nursing. Specifically, the primary investigator is a registered nurse working within a specialized schizophrenia program at a large mental health care facility. Other team members included researchers with expertise in qualitative research, schizophrenia, family caregiving, and psychiatric and mental health care.

Inclusion Criteria

Individuals were eligible to participate in the study if they were parents (biological or adoptive mother or father) and the primary caregiver for an adult child (18 years of age or older) with schizophrenia or schizoaffective disorder. We defined ‘primary caregiver’ to be the person that spends the most time (self-assessed) engaged in caregiving. Furthermore, parents were required to have provided caregiving for a minimum of one year and either be actively providing care at the time of the interview or have provided care within the last six months. This one year timeframe, which is used in similar studies (e.g. Margetic, Jakovljevic, Furjan, Margetic & Marsanic, 2013), was chosen because shorter term caregiving (e.g. weeks for example) is unlikely to involve the same insight, experiences, or effects on the caregivers’ lives (Williams, Wang, & Kitchen, 2014). Finally, parents were required to communicate in English and be capable of providing informed consent.

Participants and Recruitment

Thirteen parents of ACWS were recruited using convenience sampling through the Schizophrenia Society of Ontario (SSO), with the assistance of a gatekeeper. The SSO’s mandate is to educate, support, and advocate on behalf of people affected by schizophrenia. The organization offers education and support groups for families and friends of individuals with severe and persistent mental illness (Schizophrenia Society of Ontario, 2013).

The gatekeeper advertised the study to members of the organization through email and word-of-mouth. If parents were interested in learning more about the study, they were encouraged to contact the primary investigator by email. Individuals who expressed an interest in participating were provided a study information sheet, along with a complete explanation of the study and informed consent procedures. A consent form was provided and explained. Following written informed consent procedures, an interview was scheduled at a mutually convenient time and place.

Ethics

Research ethics approval was obtained from the Research Ethics Board of the University of Ottawa. Given the sensitive nature of the topic and its potential to induce psychological or emotional distress, time was allotted for debriefing, and parents were provided written material for local crisis support center, including contact information.

Data Collection

Data was collected through semi-structured, face-to-face interviews and a brief sociodemographic questionnaire. The primary investigator conducted nine 60-90 minute interviews between November and December of 2016. Of these, six interviews were conducted with only one parent, and three interviews were conducted with both parents together. Open-ended questions were used to explore caregiving experiences, and included, for example: ‘Can you tell me about the time that your child was first diagnosed?’, ‘What are some of the challenges/benefits you experience as a caregiver?’ and, ‘Can you tell me about what it’s been like working with the health care system?’ Parents were encouraged to speak freely about what was important to them and to share stories, anecdotes, and reflections. Efforts were made to clarify ambiguity or potential misunderstandings (Thorne, 2008). Interviews were audio recorded with the permission of the parents and transcribed verbatim.

The sociodemographic questionnaire captured information about the caregiver (i.e. age, sex, time spent caregiving, supports for ACWS, education, family income, employment status, caregiving for others, and family size) and the ACWS (i.e. age, sex, diagnosis, employment status, and income source). This data was collected to provide context to the caregivers' circumstances (e.g. other competing responsibilities, effects of caregiving on work and finances, etc.) and to allow for findings to be compared to related literature.

Data Analysis

While we began with 13 parents and 10 interviews (three dyads and seven individual parents), data from one parent was omitted because the interview was interrupted within the first 10 minutes and was unable to be rescheduled.

The transcribed interviews were analyzed using conventional content analysis as described by Hsieh and Shannon (2005). First, all transcripts were read a minimum of three times by the primary investigator to achieve immersion in the data and a sense of the whole (Tesch, 1990). Second, transcripts were read for the purpose of deriving preliminary labels (Morse & Field, 1995). This process involved highlighting exact words that captured key thoughts or concepts. Third, notes were taken of first impressions and initial decisions around analysis. Fourth, preliminary labels were identified and grouped based on how they were related to one another; these became the initial categories and subcategories. With input from the research team, categories and subcategories were further refined. Finally, we developed definitions for each category and subcategory and embedded verbatim quotes to help illustrate the findings (Hsieh & Shannon, 2005). Data from the sociodemographic questionnaire were analyzed descriptively using frequencies and percentages (see Table 1).

Rigor

Lincoln and Guba's (1985) four criteria: credibility, confirmability, dependability, and transferability were used to enhance the trustworthiness of the study. Four team members are psychiatric and mental health nurses and one team member is an expert in family caregiving. To draw upon this expertise, the team met throughout all stages of the study to discuss analyses and interpretations, which enhanced credibility of the findings. Confirmability was enhanced through exploring presuppositions about the phenomenon of interest prior to the study, and documenting these suppositions and beliefs in a journal throughout all phases of the study. Further, in planning the interview, questions were designed to be broad and allow for parents to explore their experiences and illustrative quotes were embedded into the findings. For dependability, the principal investigator was responsible for conducting all of the interviews, a study protocol outlining study methods and procedures was created, and clear explanations of an audit trail of all decisions made was kept for all elements of the study (Thorne, 2008). Finally, transferability, the extent to which findings can be transferred to other settings or situations, was enhanced by thoroughly describing parent characteristics (Lincoln & Guba, 1985).

Findings

Caregiver Characteristics

Of the 12 parent caregivers, eight identified as mothers, and four identified as fathers. Their ages ranged from 52 to 77 years. Eleven parents possessed a post-secondary or graduate degree and one completed high school. Six parents were employed, one was unemployed, and five were retired. Gross annual household income ranged from $50,000 to $175,000 with an average of more than $100, 000 per year. Two parents had additional caregiving responsibilities (i.e. other children and older parents). Time spent caregiving varied depending on the mental wellness of their ACWS. This time ranged from 24 hours per day, seven days a week when acutely ill to an average of three hours per day during stable periods. Parents also identified a number of community and social resources utilized currently or in the past, which were helpful at various points during their ACWS illness trajectories. Helpful people included family members, friends, health care providers, peers and coordinators of family support groups, and case workers. Case management and group therapies for their ACWS were provided through various means: a mental health centre, an early-intervention psychosis program, as well as community treatment teams and community mental health associations. Family support groups through the SSO, a mental health centre, and an early-intervention psychosis program were regarded as helpful for providing both informational and emotional support to caregivers (see Table 1).

ACWS Characteristics

There were a total of 10 ACWS discussed by the parents, with one family having two ACWS. Males represented nine of the ACWS described. Eight ACWS had a diagnosis of schizophrenia and two had a diagnosis of schizoaffective disorder. The ages ranged from 22 to 40 years (M = 29 years), and while most ACWS were unemployed, one worked seasonally and another worked on contracts. Nine ACWS received money from social assistance (including the seasonal and contract worker when unemployed), while one received money from long-term disability insurance. At the time of the study, three ACWS lived with their parents, though all intermittently resided within the family home.

Categories and Subcategories

The parents’ experiences of caregiving for their ACWS were described with the help of the following two categories: *‘Uncertainty and Change’* which represents parents’ difficulties identifying the schizophrenia illness at onset, resuming caregiving activities they had enacted when their ACWS’ were younger, doing things they thought they would never have to do, and facing challenges with accessing appropriate health care resources. ‘*Caregiving: Effects on my life*’ which describes the negative and positive processes and outcomes experienced as a result of their caregiving roles. Both categories are further explained by subcategories, which demonstrate the variability within these main findings (see Table 2).

Uncertainty and Change

This category reflects the uncertainties parents' felt in their caregiving roles and the changes in their parenting practices and life brought about by having a ACWS. Parents expressed feelings of unfamiliarity, unpredictability, unexpectedness, and difficultly. Within this category, the elements of *"Couldn't put a finger on it"*, *"Things I do"*, *"Things I thought I would never have to do"*, and "*How do I do what I need to do?"* are described.

Couldn't put a finger on it. Parents described having difficulty with early identification of schizophrenia symptoms. Symptoms of the illness were misattributed to other physical or mental disorders or confused with 'normal' teenage behaviour, making it hard for parents to seek appropriate care early on.

> He seemed to be the same [Son] kind of thing, but there were really quirky things that you just couldn't put your finger on it… It did not make sense in my world. But you knew there was confusion, you couldn't put your finger on it (2).

Without knowing the signs and symptoms of schizophrenia, parents had difficulty making sense of their child's behaviour. In hindsight, these were symptoms of prodromal phase or first-episode psychosis:

> But yet he was still… I would not say he was psychotic. He was with it, but to me, he seemed like he was in a really bad depression. Like, did not… like, you'd go grocery shopping and he wouldn't go in the store with you and that kind of thing (2).

For one parent, uncharacteristic thoughts and behaviours were first interpreted as a physical problem:

> And I'm going, "what the hell?" There's a big history of cancer in my family, and I thought, "Holy shit." And I dismissed the thoughts that were in my head… I had no clue what was happening. Absolutely no clue. In my head, he had a brain tumour. Because, it just seemed like… the day before he was fine (1).

Finally, parents identified subtle changes (especially in mood) resembling 'normal' teenage behaviour: "So we just figured, all my friends said, you know, 'every kid goes through that at that age… and when they're 20 they get back to being great again'" (4).

Things I do. The parents spoke about the things they needed to do once their adult child was diagnosed with schizophrenia. This included returning to child-like caregiving activities, such as doing their ACWS's groceries, preparing their meals, running their errands, and providing significant social and financial support:

> Sometimes it's the way he does stuff, and sometimes it's physical… He gets a twitch in his eye. His voice changes; he sounds like he's got a cold… his senses go into overdrive… When he starts saying, "I don't feel good. I'm not going to go to such-and-such place because my stomach feels sick" he's usually like, right on the border… he gets like a furrowed brow… the expression my son gets on his face. It's like he doesn't want to trust me, and the doctor said, "we call that perplexity" (1).

This same parent continued:

> I make all the meals, I do all the groceries… there's times still when my son doesn't want to go into a store… He's got a car, he can drive to the store. Or he'll send me an email at work saying, "Can you stop and get such-and-such" (1).

Parents provided social support for their ACWS and several parents described the financial difficulties their ACWS were experiencing as a result of their illness. Others related how they were successful in collaborating with their ACWS to ensure basic needs were met and sustained:

> To elaborate a little more on the money issue, if we didn't intervene his money would be gone by the tenth of the month… So talking to him and getting his cooperation, we asked him to give us money to hold for him, and then we dole out the grocery money as time goes on in the month, and also as the spending money… I take him to the grocery store and I spend his money, like he chooses the stuff…(5).

Parents also described how it was important for them to prepare their ACWS for future independence. Many parents felt that, currently, their ACWS were quite dependent on them for most everything. Parents did mention, however, that engaging in financial planning and family support groups and services eased this concern:

> … we're spending a lot of time… figuring out all the issues around the will, and I spent a lot of time with financial advisors figuring out how much money we will have and will that last him, a certain amount, going through all sorts of scenarios. I spent hours with our financial advisor going over that sort of thing as well (7).

In terms of providing emotional support, parents described instances where they equated their actions to those of a counsellor or educator. For them, these actions were expected when their child was young, but not anticipated now, given that their child was an adult: "We talk a lot about that with him, safe decision making… And he has improved in that he knows he can't smoke marijuana and he's actually staying away from it" (5). Related to school, this parent described coaching their ACWS in study habits:

> 'Your next step is to go to school… test it out'. And I said, 'This is totally foreign to you but you should be able to ace this. So if you need to read the chapter 10 times you read the chapter 10 times. It's just learning study habits.' So we'll do that. (2)

Things I thought I would never have to do. Parents explained how they found themselves in situations – and doing things – that they never imagined necessary. Parents attributed these actions to their child's schizophrenia diagnosis. They described instances involving the police, as well as engaging in preventative actions to ensure safety and rearranging their home and social environments.

All parents described interacting with police at least once, and often multiple times, in response to situations concerning their ACWS. Parents reported how they were required to call the police out of fear for their safety, the safety of their child, or the safety of others. Other times, police involvement was initiated by the health care team because of legal stipulations around treatment adherence:

> I've got to phone mobile crisis [mental health crisis response team] now and … I was really scared [ACWS] was going to do something crazy like kill me or something. So the police eventually arrive, first the mobile crisis then the cops and then, as quick as the destruction [ACWS] made happened, it stopped (6).

Police interventions were distressing, and as one parent described, left them feeling vulnerable. They feared that their safety might be compromised because of taking this action:

> But he was so agitated that I phoned the police. And once you're there, you've done that, then you open up the doors to whatever's going to come down the driveway… we talked to the police officers who felt that he should go to the hospital, and I said no, because I was pretty sure that he was not sick enough… There didn't seem to be a bed, and, you

> know, I just didn't want to get into this thing where we take him and they send him home with us, and he's angry that we've called the police … you know? (3)

When parents described preventative actions, they spoke of legal measures taken to ensure guardianship, power of attorney, or substitute decision making. These legal measures were taken to ensure they had decision-making responsibility should their ACWS become incapable of doing so for themselves: "In theory, because we are our son's guardians… we could have forced the issue. But we're not going to go to court every time somebody says no." (3). When these measures were not required, parents felt relieved:

> We did go to a lawyer when he first got sick and we do have the trust but also the forms that he gives us power of attorney... But we didn't have to, he always allowed us to be there at any appointments or any decisions. We're very lucky (8).

Though not a formal, legal measure, parents learned to anticipate potential safety risks and altered their home and social environments accordingly. Some parents were fearful, based on past experiences or worry, that their ACWS might die by suicide. Parents described their fear and anxiety while walking with their child near busy streets, strategically placing themselves closest to traffic: "I'd go to the hospital and we'd go walking down the road, and I'd walk on the road side in case he wanted to jump in front of a bus" (4). As a shocking example, while on vacation, one parent described hiding knives to manage suicide risk.

How do I do what I need to do? Parents described significant difficulty with timely access to appropriate health care resources for their ACWS. This problem was universal during the early stages of the illness and many parents continued to experience challenges as a result of the particularities of the illness. It was not clear to many parents early on that visiting a family doctor was the best way to seek care or referral. Furthermore, when parents knew what care was needed, lack of insight on behalf of their ACWS, was particularly challenging when they maintained capacity for treatment decisions despite medication nonadherence. Parents described needing to wait for the worst case scenario in order for any intervention to take place.

Parents described the distress experienced when their child refused treatment; so long as their child did not pose significant risk to themselves or others, treatment could be declined. Parents witnessed their child's illness state worsen and described feeling significantly distressed and helpless to do anything about it. Parents continued to manage their child in the home, watching them slip further and further into the illness, just waiting for "the worst" to happen.

> So each time he is not taking medication, he's living in turmoil and distress, and the only advice anyone could give me was, 'Just take care of him the best you can, wait until he gets so sick that we can certify him.' So you had to sit there, and watch him…. Well the worst thing that can happen, you know, is suicide for Christ's sake. Anyway, so each time I had to spend months and months, you know, waiting for him to become a harm to himself or to another person, or to not be able to care for himself, under the eyes of the law or the psychiatrist who has diagnosed him. That's hard… So, if you can fix anything for parents, that's the thing to fix. You know, being told to watch somebody get so bad that then you can bring the law in basically (4).

As a result of their inability to access the mental health care system, the parents in this study came to understand that their ACWS needed to pose significant homicidal or suicidal risk, or be involved in a criminal act, in order to receive intervention when needed.

> You can't just walk in and say, 'We need help' … It needs to be, the way the rules are, it has to be a crisis where somebody is about to get hurt or it's almost a criminal act …. To be able to get some attention, to get some access (2).

Parents trying to seek more immediate care through emergency departments described the ineffectiveness of this route:

> We would go to the emergency and they would just send us home. So I talked to his psychiatrist and he said just keep going back and we had to just keep going back to the emergency. I think we went about five nights and sat there all night of course… And it's sort of like, unless you go to emergency and he wants to kill himself or kill somebody else, then they just send him home (8).

Navigational issues not only prevented early treatment for ACWS, but families were then exposed to greater levels of stress when they couldn't engage in care:

> The system isn't geared to really supporting people quickly… we wasted quite a bit of time before we could get on the right path as it were. And it's very stressful of course: you're going down wrong roads and having to come back and there's conditions continuing and the stress is continuing in the family all that time (7).

Caregiving: Effects on my Life

The parents spoke at length about the negative and positive effects on their lives because of being caregivers for ACWS.

The bad. Psychological distress was described in a variety of ways. Parents blamed themselves and felt guilty about child's mental illness. Worry, fear, and feeling helpless were difficult, but common experiences for these parents and all described the devastation stemming from their child's schizophrenia:

> He would see them sitting in the corner of the living room, making fun of him. Like there were times he would say to me, "Mom, did you see that?" I said, "What do you see?" and then he'd start telling me what he saw and I was like, oh my god… like what he sees and

> what he feels. And that's where I was just, I was starting to feel the devastation of his world … I think we went into a devastating period … and then it's like denial. This can't be happening… it just can't be happening. I mean, who does this happen to? (2)

In terms of physical changes, some parents spoke about their own difficulties with depression and being prescribed antidepressants and many parents specifically spoke about difficulties with sleep. Lack of sleep occurred because of their hypervigilance in monitoring their ACWS and overall distress making sleep difficult. While her son was quite ill, one parent based her own sleep schedule on her son's erratic pattern: "… I just kind of napped my way through the day while he was sleeping" (2), and other parents reported how the symptoms of schizophrenia made sleep quite difficult to attain:

> And when he was manic and walking around at all hours of the night, it's hard to get any sleep, because we'd be sleeping on edge all the time… you're always wondering what's going to happen… just the walking around when you're trying to sleep, and it's right outside your door… (5).

More drastic measures around sleep were described by some caregivers because of their ACWS' unpredictability. This led to psychological distress, such as fear, and physical health consequences:

> I've attempted to sleep in my car. I don't fit in my little car very well. There's locks changed on different doors in my house... I've slept with the phone in the room so that if I need to get help and think ok I'll have to get up. I'm supposed to sleep with a sleep apnea machine but I don't always because he's wandering around the house (1).

Some parents spoke about the impact of caregiving on their social and family life, and every caregiver described ways in which caregiving for ACWS affected decisions around work and career. There were alterations in working hours or time-off for some, while others declined job opportunities because of unpredictable care needs. For example, one parent explained the need to prioritize supporting her ACWS through a longer phase of stability without relapse before re-entering the workforce. Another parent explained how being a caregiver affected his career and work with colleagues: "I was supposed to go to [international] for meetings… I had to just say 'I'm not going,' and you know, people were disappointed. They wanted me to go because they needed that particularly and I just didn't do it" (7).

Overall, caregiving was noted to affect parents' ability to engage meaningfully in the workplace. Some parents made the decision to retire early for their own well-being or to maintain a steady and secure home environment for their ACWS. Other parents continued to work into later years to recover financial losses as a result of caregiving.

The parents explained how they felt the effects of stigma and several parents feared the reactions of others and opted not to disclose their child's diagnosis as a result. When reflecting on her interactions with colleagues, one parent stated:

> I always went to the staff room for lunch, but I had a policy of never asking anybody else about their kids, because I didn't want them to ask me questions. So I never asked questions, and I just hoped no one would ask me (5).

Keeping their caregiving experiences hidden due to perceived stigma was echoed by this parent who described it in the broader social context:

> It's like an underground network… I mean, you go to a Christmas party and everybody is coming up to you, you know, 'we heard about your son' and then the next thing you know, 'My brother, my daughter…' If I had never said anything, I would have never known. They all think of psych as a dirty darn secret. And that's the stigma (5).

The good. Parents in this study also recounted positive outcomes resulting from their caregiving role, such as involvement in non-profit and volunteer organizations. These outcomes were described as being meaningful. Their involvement stretched from social housing committees and building support networks for persons with schizophrenia, to fundraising initiatives and guest speaking or facilitating family support groups: “I volunteer… I help organize things, but I also go for my own learning” (9). At times, this altruistic involvement also held meaning for the health of their ACWS:

> People are referred to them [supportive housing agency] and then they ask me if I can talk to people and then I can refer them to other places … I was always trying to help [son] become more independent and one of the things would be to help him find a place to live… I’m on the board, I’m a visiting volunteer, and I’m on the federal fundraising committee… (8)

In addition to organized activities, parents also engaged in informal activities, such as becoming informal resources to educate, support, or network with others. One parent described meeting with her son’s friends after he became ill to help increase their understanding:

> …I said, ‘I’m going to meet you. I’ll answer questions. Ask.’ … So they still stay in touch with him. The relationship is not the same because he’s not the same, but they still get together; they still invite him places (1).

Another parent described being a resource person for colleagues:

> I have counselled or helped find resources for other staff members who are having issues with family members, because one or two people have an idea of what’s going on. So they’ll come and say, ‘Do you happen to know…’ they won’t ask me directly, about

> what's going on in my house, but they'll say, 'Do you think that you could help me find…' and of course I do (3).

Being a caregiver was important to the parents, who felt that it enhanced their own personal growth. They considered themselves to be more understanding of people and sensitive to others facing struggles. Parents expressed greater appreciation of the complexity of underlying issues facing vulnerable populations, such as those that are homeless. Greater awareness put their lives into perspective, as one parent clearly stated: "…you really learn what's important in life when your child is sick because all of a sudden, work, or being productive, or the silly things that you worry about aren't important anymore" (8). There was also a sense of gratitude, as another parent expressed:

> If it hadn't had been for [daughter] being who she was, I wouldn't do the things that I do. I kind of like that. I always look at that and think, I'm grateful for that; grateful for [daughter] to be who she was, for me do the things I've done in my life. So it's kind of nice in that way… so that's my mission in life you know? To help others (6).

Discussion

The parents in this study spoke at length about their experiences of being parent caregivers for their ACWS. Through their stories, parents described periods of uncertainty, which were related to not knowing what was happening to the child and subsequently not knowing how to ensure appropriate care because of access and navigation issues. At times, parents explained how they waited for the worst to happen and required police intervention to get their child needed help. These experiences caused tremendous distress for parents who expressed intense feeling of fear, worry, and devastation. Interestingly, the parents also identified a number of positives stemming from their caregiver roles. Three important considerations stemming from the parents’ experiences warrant further discussion: Access and Navigation of Resources; Police Intervention; and Distress.

Access and Navigation of Resources.

The parents’ problems with access concerned barriers to getting necessary mental health care, while problems with navigation related to not knowing where to turn for appropriate services (i.e. which services were needed and where they were located). This echoes previous descriptions of relatives’ caregiving experiences in schizophrenia in the literature. For example, relatives express services’ structure and functions as being obscure and unknowable (Wainwright, Glentworth, Haddock, Bentley, & Lobban, 2015), and authors suggest that families’ challenges with accessing resources would be better addressed through implementing policies that better integrate mental health care through primary health care services (Jack-Ide, Uys, & Middleton, 2013) described families challenges with accessing resources and recommended policies that provide mental health care through primary health-care services.

In the early phases of the illness, problems were not due to a lack of available resources, but rather parents struggled to decipher what services they required. They were not yet familiar with what care was available or how to gain access to said care, and they described losing valuable time going down wrong paths. Lost time resulted in greater distress for the family and their children becoming more ill. It is well-known that delays in treatment result in greater symptom severity and poorer social and global functioning, thus it is critically important that people suffering from a psychotic illness receive treatment quickly (Penttilä, Jääskeläinen, Hirvonen, Isohanni, & Miettunen, 2014). Parents explained how there was no formal guidance for them, and while there are manuals and online resource listings to help families navigate the various local services (e.g. Recovery Connections & Family Advisory Committee, 2013), it appears as though these parents were not benefitting from them. Policies need to mandate the linking and coordination of resources in order to alleviate families' burden, enable early diagnosis and treatment, and reduce the need to travel and search for resources. One way to alleviate some of these difficulties is to better embed these resources in the community through primary health-care services (Jack-Ide, Uys, & Middleton, 2013).

Parents also stressed the need to improve access to care when their ACWS refused treatment because of poor insight. Lack of insight is common in schizophrenia because the affected individual, when psychotic, has difficulty differentiating between reality and their hallucinations or delusions (Baier, 2010). Parents felt helpless and distressed as they watched their child deteriorate without treatment and based on the experiences of the parents included in this study, it seems as though parents have to wait for their child's condition to deteriorate significantly before they can act on their behalf. As per the Mental Health Act (1990), to initiate treatment, persons with mental illness need to demonstrate imminent risk to self or others. For our parent participants, these strict criteria posed a tremendous barrier to supporting their ACWS in the initiation of treatment.

Given the severe and potentially damaging effects of delayed psychiatric care, an area requiring further exploration is the use of advance directives, created when an individual is in the stable phase of illness. The use of advance directives in psychiatry is a relatively recent phenomenon; there exists both a paucity of literature in the area and diverse views (Sarin, 2012). Advance directives aim to respect autonomy, by having the individual decide treatment wishes while well, which are then enacted when they become ill. However, Sarin (2012) explains how it is not possible to reconcile autonomy and choice, with the possibility of involuntary treatment, and thus advance directives are difficult to enact. Conversely, Srebnik and colleagues highlight the importance of having access to patient preferences even when they are unable to articulate them. This results in decreased perceived coercion, family conflict, and might mitigate the need for more drastic measures, such as police intervention (Srebnik et al., 2005). Furthermore, Swanson and colleagues (2006) advocate the utility of advance directives in clinical practice, but stress their poor completion rates. The authors recommend planning structured sessions with capable patients to better incorporate advance directives into practice, given that information alone results in a completion rate of only 3% completion compared to 61% when done in a facilitated session (Swanson et al., 2006). Researchers and policy makers should explore potential facilitators and barriers, as well as ethical challenges and benefits of advance directives (Srebnik et al., 2005; Swanson et al., 2006).

Police Intervention

All parents described interactions with police. Police were contacted by parents because of fear for the safety of their child, self, or others. This finding was somewhat expected given that approximately one third of persons experiencing their first psychosis related to schizophrenia come in contact with police – this equates to double the estimates in the general population (Schumann, Asmal, Chiliza, & Emsley, 2017). Through their recounts, it became clear that parents have multiple concerns regarding police intervention and some parents described frustration with police for not being sensitive to the effects of their child’s illness. The fears expressed by the parent participants in our study echo a number of tragic cases involving police and persons with serious mental illness. News reports describe interactions resulting in death, when fake weapons are mistaken for real weapons (Helmer, 2016), or when excessive force is used during an arrest (Yogaretnam, 2016). A recent investigation into deaths stemming from police intervention found that half of reported deaths involve a person with a disability (Perry &

Carter-Long, 2016). The investigators concluded that police officers become default responders to mental health calls and that people with psychiatric disabilities are presumed to be dangerous (Perry & Carter-Log, 2016). By virtue of their training, police are fundamentally concerned with public safety and it is well-known that persons suffering from symptoms of mental illness are inappropriately directed towards correctional, rather than health, settings (Perez, Leifman, & Estrada, 2003).

Diversion programs aim to ensure that persons requiring health care do not fall into the legal system (Baillargeon, Binswanger, Penn, Williams, & Murray, 2009). Crisis intervention teams, consisting of police officers and mental health care professionals (such as nurses), are one type of diversion strategy. These crisis intervention teams aim to resolve psychiatric emergencies without resorting to arrest (Baillargeon, Binswanger, Penn, Williams, & Murray, 2009). Mental health nurses can work collaboratively with police officers on mental health crisis teams, and research suggests that appropriate training allows for better prevention of escalation, greater effectiveness using nonphysical actions, and improved knowledge of crisis management strategies (Compton et al., 2011). Taking an interprofessional approach to mental health emergencies in the community, might help to ensure that psychiatric needs are recognized, understood, and appropriately responded to early on.

Distress

Distress was a prominent topic discussed by all parents. This distress was a direct consequence of their caregiving roles, which is consistent with current literature (Hanzawa et al., 2013; Ong, Ibrahim, & Wahab, 2016; Schulz, Hebert, & Boerner, 2008). Caregivers (in general) are at greater risk for developing psychiatric disorders, such as anxiety, depression, or trauma disorders, compared to non-caregivers (Schulz, Hebert, & Boerner, 2008; Schulz & Sherwood, 2008), and this risk is compounded for caregivers for persons with mental illness (Hanzawa et al., 2013). The hereditary nature of mental illness means that caregivers commonly have pre-existing mental disorders that exacerbate under caregiving stress, or are predisposed to the development of new disorders (Hanzawa et al., 2013; Schulz, Hebert, & Boerner, 2008).

Parents in this study spoke of their challenges in maintaining their mental health; some described periods when they required medication to ease anxiety or depression. These symptoms were most common when their ACWS were very unwell, and parents expressed feelings of self-blame, guilt, worry, fear, and helplessness, which perpetuated their poor mental health. Additionally, getting enough quality sleep and maintaining a regular sleep schedule was a problem identified by most parents. Groups providing support, education, counselling, and respite services are important interventions to support caregivers' psychological health and well-being (Dangdomyouth, Stern, Oumtanee, & Yunibhand, 2008). Unfortunately, the parents in this study, and in many others (Blomgren Mannerheim, Hellström, Muhli, & Siouta, 2016; McAuliffee, O'Conner, & Meagher, 2014; Wiens & Daniluk, 2009) have great difficulty identifying the services they require and/or navigating the systems housing the services. Several health care providers, such as nurses and social workers, are well-positioned to help bridge this gap, and it is important that providers working with schizophrenia caregivers are knowledgeable about local resources and how to gain timely access to them.

From a more personal perspective, our findings suggest that nurses can work with parent caregivers to help them develop adaptive coping strategies, which will in turn ease their distress and help them to function healthily within their role. Working from a strengths-based perspective, (Gottlieb, 2013) nurses can help caregivers to mobilize, capitalize, and develop individual strengths that promote health and well-being. Furthermore, nurses are in a key position to facilitate groups, such as information sessions, patient and family education, and family peer-support, which improve social connections and support. Improving social support and reducing distress can improve the overall well-being of caregivers while also supporting the recovery of ACWS (Ong, Ibrahim, & Wahab, 2016). While this study did identify some positive experiences of caregiving, further exploration of these experiences is warranted. Developing models that describe caregiving resilience in this population would be useful to direct future research.

Limitations

There are four limitations to consider when interpreting the findings of this study. First, as with all qualitative studies including interviews, findings are limited to the extent of parents' disclosure of the phenomenon of interest. Caring for an ACWS is a personal experience, and parents may have censored their experiences and stories to avoid feeling uncomfortable or judged. To minimize this threat, the researcher (LY) conducting the interviews disclosed that she worked as a psychiatric and mental health nurse and that she is passionate about improving the lives of persons with schizophrenia and their families. Parents were also reminded that all data would be de-identified and their participation would remain anonymous. Secondly, recall of the phenomena of interest and how one might experience their role can change over time. Parents interviewed reported that their ACWS were in more stable phases of their illness at the time of the interview and experiences described often occurred several years earlier. Many parents remarked that their explanations would likely be quite different had they been interviewed at the height of their child's illness. Third, there is always a possibility of bias or misrepresentation of the parents' experiences. This risk was reduced through reading every quote and exploring associations, relationships, and patterns in the data. Furthermore, convergent and divergent ideas were presented and discussed with the research team (Appleton & King, 1997; Denzin & Lincoln, 2005) who had expertise in the phenomenon of interest and qualitative methods. The fourth limitation concerns implications related to socioeconomic status. The parents of this study were in an economic bracket greater than the national average, with the average annual family income being greater than $100, 000. This limits the transferability of the findings to parent caregivers living under different economic realities.

Conclusion

Parent caregivers for ACWS experience tremendous distress in their roles. This distress manifests through feelings of worry, fear, and devastation, and at times contributes to a reduction in their own mental health and well-being. When police intervention is required to initiate treatment, parents require additional support because of the possible implications on their relationships with their ACWS. Interestingly, while our findings resonate with an already abundant area of research concerning difficulties with access to resources in the mental health system, parents emphasized that the problem was not a shortage of resources, but rather difficulties locating, and entering in to, appropriate services. Strategies are needed to aid parent caregivers with the logistical barriers to existing resources. Finally, amidst their negative experiences, the parents described several positive outcomes associated with their caregiving role. More research is needed to understand these positive outcomes, what contributes to their development, and how to foster them within clinical practice.

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Table 1
Caregiver Characteristics

Age (yrs)	Relationship to ACWS	Time since diagnosis (yrs)	Education	Gross Household Annual Income ($1000s)	Employment Status	Caregiver for Others
74	Mother	n.p.	College/University	100 – 125	Retired	No
77	Father					
63	Mother	7	College/University	100	Retired	Elderly parents (social support – appointments, phone calls, visits)
71	Father					
66	Mother	12	College/University	150 - 175	Employed	No
n.p.	Father					
60	Mother	7	College/University	50 – 75	Employed	No
60	Mother	4	High School	75 - 100	Employed	No
60	Mother	2.5	College/University	100 – 125	Retired	No
54	Mother	6	College/University	100 - 125	Unemployed	No
56	Mother	3.75	College/University	125 - 150	Employed	No
52	Father	7	College/University	> 100	Employed	Two teenage children

n.p. = not provided

Table 2

Categories and Subcategories

Category	Subcategory
Uncertainty and Change	Couldn’t put a Finger on It
	Things I do
	Things I thought I would never have to do
	How do I do what I need to do?
Caregiving: Effects on my Life	The Bad
	The Good

Chapter Five

Integrated Discussion

Thesis Summary

The purpose of this Master's thesis was to better understand how parent caregivers of adult children with schizophrenia (ACWS) experience their role. This phenomenon was studied in two phases. First, I conducted a qualitative evidence synthesis to identify and describe how parent caregivers of ACWS articulate their caregiver roles and experiences according to existing literature on the topic (Chapter Three). Second, I used a qualitative descriptive design to explore how parents experience their roles as caregivers for ACWS (Chapter Four). A manuscript was prepared for each study for submission to two separate academic peer-reviewed psychiatric nursing journals.

Manuscript One: Qualitative Evidence Synthesis

The Joanna Briggs Methodology for qualitative systematic reviews ([JBI], 2014) was used to answer the following research question: "According to recent qualitative research literature, how do parents of adult children with schizophrenia (ACWS) experience and describe their caregiver role?" The search strategy was developed with the assistance of two library scientists and was conducted in the MEDLINE, PsycINFO, and CINAHL databases. Research evidence was reviewed systematically using a two-level screening process (title and abstract then full-text screening) and consensus meetings were held with three authors after each screening to resolve discrepancies. The search strategy produced a total of 2, 321 citations. After removing duplicates and those studies incompatible with inclusion criteria, a total of 5 studies were incorporated into the review. Data was extracted and entered into summary tables reflecting study characteristics, parent caregiver characteristics, and study outcomes (i.e. themes and supporting quotes). JBI's (2016) checklist for qualitative research was used to assess quality of the included studies. Scores ranged from seven to nine (out of 10).

After aggregating and comparing the original findings for similarities and differences, I identified the following five categories, which were supported by eleven subcategories: *'Access, Availability, and Appropriateness of Resources'; 'Grieving Losses'* (*Losses related to Child; Losses related to Self*)*; 'Psychological Distress'* (*Guilt; Devastation; Fear; Worries about an Uncertain Future*)*; 'Effects on Family'* (*Effects on Family Relationships; Responsibility*)*;* and *'Framing the Experience'* (*Positive Thoughts; Religious or Spiritual Beliefs; Personal Growth).* Parents included in the reviewed studies went beyond descriptions of loss related to their child, and spoke of multiple personal losses they experienced as a result of their caregiving role. Caregiving across an unpredictable and chronic illness trajectory left parents unable to fully pursue their own personal goals and aspirations. Furthermore, the parents described multiple social losses and isolation because of caregiving demands and significant psychological distress was experienced as a result of caregiving. Finally, an encouraging finding was that parent caregivers of ACWS were able to frame their experiences in positive ways to support a more healthy perspective.

Manuscript Two: Qualitative Study

Interpretive Description was used to explore how parents experience their roles as caregivers for ACWS. Thirteen parents of ACWS (18 years of age or older with a diagnosis of schizophrenia or schizoaffective disorder) were recruited through the Schizophrenia Society of Ontario and data were collected via semi-structured, face-to-face interviews and a brief sociodemographic questionnaire. The parent caregivers experiences were described with the help of two categories, supported by six subcategories: *'Uncertainty and Change'* (*Couldn't put a finger on it; Things I do; Things I thought I would never have to do; How do I do what I need to do?*); and *'Caregiving: Effects on my life'* (*The bad; The good*).

Parents emphasized their problems with accessing and navigating the mental health system, and spoke at length about police intervention. And while negative experiences and distress dominated the data, parents also reported positive outcomes associated with their role. Many parents were involved in non-profit and volunteer organizations supporting persons with schizophrenia and their families. They described instances in which they served as both formal and informal resources to family, friends, and co-workers. The development of personal growth factors, such as increased understanding, sensitivity, and empathy were further cultivated in their caregiving roles.

Integrated Discussion

Through this Master’s thesis enquiry, I identified two cross-cutting considerations in addition to the important findings discussed in the two manuscripts. First, parents have difficulty using and understanding the resources available in the mental health care system. Second, parents experience distress in their caregiver roles, and this distress is often induced or worsened as a result of barriers to treatment for their ACWS. These considerations will be discussed below in relation to the extent literature. Furthermore, I provide implications for practice, policy, education, and research.

Using and Understanding Resources

Parent caregivers struggle to use and understand the resources available in the mental health system. Problems with using resources concerned barriers such as assessment by a specialized mental health care provider and urgent referrals to necessary mental health care services. Problems with understanding resources related to parents not knowing where to turn for appropriate care (i.e. which services are needed and where are they located).

Parents experienced significant difficulty in securing mental health care services for their ACWS at the onset of their illness. Parents identified this critically important period as especially confusing; they recounted hours of lost and wasted time trying to establish contact with the mental health care system. According to the Canadian Psychiatric Association's (2006) recommended benchmarks, persons experiencing a first episode psychosis should be seen within 24 hours for an emergent indication, within 1 week for an urgent indication, or within 2 weeks for a scheduled indication. Indicated benchmarks are based on the premise that duration of untreated psychosis (DUP) must be minimized to promote better long-term outcomes (Yung & Barnaby, 2013). When parents are unable to access and navigate the mental health care system efficiently, these benchmarks are not met, thus contributing to a worsening of symptoms and stress on the family (Yung & Barnaby, 2013). Parents who were unable to secure mental health care for their ACWS witnessed their children's symptoms worsen, to a point where they became concerned about their safety and the safety of others.

Safety of and risk to self and others is a leading reason for required psychiatric evaluation and subsequent involuntary admission to hospital (Ziegenbein, Anreis, Brüggen, Ohlmeier, & Kropp, 2006). The research presented in this thesis reveals how when parents are unable to manage the symptoms of schizophrenia at home, that they resort to seeing emergency care. The decision to bring their ACWS to the emergency department was made either independently or based on recommendation by health care professionals. Although the parents were told that the emergency department is the quickest and most direct way to access mental health care, the emergency department environment can exacerbate symptoms and lead to poor health care experiences because of limited privacy and quiet spaces, use of electronic equipment, and inadequate mental health preparation for staff (Clarke, Dusome, & Hughes, 2007; Innes, Morphet, O'Brien, & Munro, 2014). Furthermore, there is a growing effort to decrease visits for symptoms of mental illness that can be managed in the community (van den Berg, van Loenen, & Westert, 2016). Unfortunately, research suggests that majority of persons first entering the mental health care system do so through the emergency department, and uptake of subsequent outpatient care is limited (Gill et al., 2017). Given the existing stigma surrounding mental illness in the emergency department, patients requiring psychiatric care are often met with contempt by emergency department staff (White, 2010; Sulzer, 2015). Strategies designed to limit reliance on the emergency department for access to initial care are needed and effort should be made to ensure all emergency department staff are adequately prepared to provide mental health care.

Improving Use and Understanding of Resources

Two different approaches to the resource problems described by parent caregivers will be discussed here. The first, integration of system navigators, is a ‘band-aid’ or temporary solution addressing the navigation of our problematic labyrinth of a mental health care system. The second approach includes investing time, energy, and resources into transforming the current system, so that systems navigators are unnecessary.

System Navigators. To help people navigate the mental health care system in its current state, there is growing interest in systems navigators. Systems navigation programs were first introduced in oncology in New York in the 1990’s. The original intent was to expedite diagnostic and treatment services, while facilitating access to care (Freeman et al., 1995). Navigators now exist in a number of health care specialities, including mental health care. The integration of systems navigators should be based on sound policy identifying necessary education, training, and scope and public health care systems should be more proactive in defining and measuring outcomes to justify their use in practice (Valaitis et al., 2017). In a pilot program, Kelly and colleagues (2014) found that compared to a control group, persons assigned a peer navigator reported fewer health complaints and preferred to seek care through primary care providers rather than the emergency department. Furthermore, increasing peer support, and subsequently improving social connections, is an important priority for better overall quality of life for persons with schizophrenia (Avasthi, 2010). Clearly, the use of systems navigators, and ideally the use of peer system navigators, deserves further attention. Work is needed to understand how to best integrate these individuals into the circle of care and interventions further supporting the effectiveness are needed to support policy change and allocation of resources.

Transforming the System. The current mental health care system requires rapid transformation to provide fast, equitable, and easier to access services. In their discussion paper titled, *"Every door is the right door: Towards a 10-year mental health and addictions strategy,"* Ontario's Ministry of Health and Long-Term Care (2009) described the mental health care system as fragmented; people go through too many doors and struggle to find the services they need. Published almost a decade ago, the problematic issues of that time continue to plague parent caregivers, as evidence by the results of this Master's research. The Ministry states that the current system only helps people who manage to reach services, instead the mental health system should be accessible to all (Ministry of Health and Long-Term Care, 2009). Services must be cohesive, rather than operate in silos, and be available close to home, particularly for people living outside of large urban centres (Ministry of Health and Long-Term Care, 2009). This emphasis on rural and remote access is particularly important because rural mentally ill individuals are often more symptomatic than their urban counterparts (McCabe & Macnee, 2009). Limited mental health care is available in rural and remote areas and this geographic disparity deserves attention.

Advanced practice nurses and Nurse Practitioners have a long history of working within rural settings (Registered Nurses’ Association of Ontario, 2015) and can operate and practice within satellite mental health clinics. Satellite sites, which are linked to a parent site often located in a large urban center, offer the same services as their parent site in rural and remote locations (McCabe & Macnee, 2009; Registered Nurses’ Association of Ontario, 2015). Satellite sites run by Nurse Practitioners with experience in psychiatry offer several advantages. First, Nurse Practitioners are educated to address holistic health needs including primary prevention measures such as screening for metabolic illnesses. Second because Nurse Practitioners are permitted to prescribe medications and provide referrals for diagnostic testing, they are equipped to oversee mental health treatment – psychiatrists then can assume a consultation role (McCabe & Macnee, 2009; Registered Nurses’ Association of Ontario, 2015). Finally, with Nurse Practitioners paid through salary rather than a fee-for-service structure (like many psychiatrists and other physicians), differing incentives support the provision of a wide variety of biopsychosocial approaches for a more holistic approach to health care (Olsen, 2009).

As discussed above, the emergency department continues to be the primary access point for individuals into the mental health system (Clarke, Dusome, & Hughes, 2007). Unfortunately, emergency care is exactly that, emergency care, where pharmacologic interventions are forefront. In the current healthcare context, where financial and human resources are limited, admissions to hospital are short, discharge plans are limited, and continuity of care between hospital and community is problematic (Foli-Anderson, 2014). Implementing urgent mental health care clinics is one way to provide rapid specialized services outside of the ED, which would increase ease of access for the general population. Urgent care clinics for medical needs are common, and while individuals experiencing psychiatric symptoms are able to present for care, practitioners working within these centers often lack appropriate psychiatric and mental health expertise when compared to mental health urgent care clinics (Sunderji, Tan de Bibiana, & Stergiopoulos, 2015). As a real example of a functioning and effective mental health urgent care clinic, we can refer to the Mental Health Crisis Response Center opened in 2013 in Winnipeg. This centre provides 24 hour per day, seven day per week walk-in and scheduled urgent care, and is also home to their mental health Mobile Crisis Team. The centre was designed for adults experiencing anything from personal distress to active suicidal ideation, and their mandate includes assessment and crisis intervention while transitioning their patients to longer-term mental health services. This clinic has decreased emergency department use and reduced hospitalization rates (Winnipeg Regional Health Authority, 2017). Notably, these services can alleviate some uncertainty at the illness onset as they are easily accessible in a timely manner and professionals coordinate next steps in care in lieu of parent or other family caregivers.

Caregiver Distress

The findings from the qualitative evidence synthesis and the qualitative study highlight the distress experienced by parent caregivers for ACWS. Common elements of distress between the two studies were guilt, blame, devastation, fear, and worry. Psychological distress perpetuated by difficulties securing mental health care was also a common finding.

Psychological distress occurred throughout the illness trajectory, and the way in which distress was experienced varied depending on the life circumstances of the parents. Interestingly, recent statistics show that significant psychological distress is reported by Canadian caregivers providing care for as little as two hours per week (Statistics Canada, 2013). Parent caregivers of ACWS in my study reported spending approximately 21 hours per week in caregiving activities

(Young, Vandyk, Jacob, McPherson, & Murata, 2017), and a large community study in the United States reported that caregivers for a person with a mental illness typically provide care for an average of 32 hours per week (National Alliance for Caregiving, 2016). Clearly, with the additional time spent caregiving, parents of ACWS require more intense support to minimize their burden. Furthermore, many parents described experiencing tremendous guilt immediately following their child's diagnosis. Some parents blamed themselves for not getting their child into the mental health care system sooner, and all parents recalled the time preceding diagnosis as being incredibly stressful. They described losing a lot of valuable time going down wrong paths, unable to secure the proper resources for their ACWS. During this time, parent caregivers in both studies described accumulating stress within the family unit, and parent caregivers are known to feel failure and incompetence related to 'missing' key signs and symptoms of the illness (McCann, Luban, & Clark, 2011).

Parent caregiver distress was also prominent during acute exacerbations of their child's schizophrenia, and was tied explicitly to their ACWS refusing treatment. Parents described watching the devastating effects of the illness take over while feeling helpless and powerless to do anything. Parents were on edge, needing to be hypervigilant in their monitoring to respond to potential serious risks to their child, themselves, or others. Unfortunately, parent caregivers report believing that they must wait for the absolute worst to happen (i.e. imminent risk of harm to self or others) before they can adequately advocate for treatment. Caring for a loved one who refuses treatment (and has the decision-making capacity to do so), but lacks insight into their illness can be devastating for families (Siegel, 2013). Contributing to this, is the dynamic of the parent caregiver and ACWS relationship. When compared to other caregiving dyads, persons with schizophrenia and their caregivers have relationships that are, more characteristically protective or dependent (Pinheiro, Nunes, Carvalho, Mendes, & Rocha, 2017). Furthermore, parents described little to no sleep during acute phases of their ACWS's illness due to stress, worry, or fear, and these acute stressors can lead to more serious mental health-related consequences (Lasebikan & Ayinde, 2013), such as anxiety, depression, or post-traumatic stress disorders (Hanzawa et al., 2013). Parent caregivers benefit from learning how to positively cope with their stress, and unhealthy coping is said to negatively affect their functioning (Chadda, 2014). Shah, Sultan, Faisal, and Irfan (2013) maintain that mental health care systems are lacking adequate services to provide psychological support to caregivers. Reasons for this could be related to inadequate staffing levels in psychiatric settings, where health care professionals describe the need to prioritize crisis prevention over family intervention (Rose et al., 2004).

Nurses and other health care providers can teach adaptive coping strategies to help ease caregiver distress and prevent further deterioration or development of psychological disorders (Ong, Ibrahim, &Wahab, 2016). One way for nurses to begin developing therapeutic relationships with families, and increase their perceived levels of support, is through implementation of routine family practices on psychiatric wards (Sveinbjarnardottir, Svavarsdottir, & Wright, 2012). Nurses can also use a strengths-based nursing approach (Gottlieb, 2013) and integrate principles of Cognitive Behavioural Therapy ([CBT] Beck, Rector, Stolar, & Grant, 2008) while interacting with families in all settings. These approaches promote a more positive orientation to caregiving and problem solving. Finally, there are local resources designed to address the needs of family caregivers for persons with schizophrenia. Early intervention psychosis programs and schizophrenia organizations containing family education and support components were described as being helpful for many parents. These support services helped caregivers address their emotional, psychological, social, and informational needs. In a review exploring schizophrenia family caregivers' interactions with health care providers, one of Klages, Usher, and Jackson's (2017) main findings was that parents identified caregiver support groups as being particularly valuable during periods of distress.

Nursing Implications

The research presented in this thesis supports specific nursing implications for practice, policy, education, and research.

Implications for Practice

Parents often feel helpless when their ACWS decompensate and they are legally unable to initiate or re-initiate treatment. Nurses, who practice within a family-centered care model, are required to assess the health and well-being of family members and the family unit. As such, nurses are ideally positioned to advocate for and include parent caregivers into the care team. By working with ACWS and their parent caregivers in periods of wellness, nurses can facilitate conversations around relapse prevention and crisis management. This form of advanced planning is well within the scope of a psychiatric and mental health nurse, and is likely to alleviate some of the uncertainty and helplessness felt by parent caregivers during acute phases of the illness.

Furthermore, with training, nurses can use principles of CBT and strengths-based nursing care in their interactions with family in order to help caregivers adopt or maintain a positive orientation toward their role. Nurses can assess the specific individual needs of family members and make recommendations or referrals to community resources best fit to address their needs. In order to help families adequately navigate the mental health care terrain, nurse managers can ensure that staff receives education and training about local resources and how to access services. Information guides containing contact information for support services should be given upon admission to a psychiatric unit and displayed clearly at entry ways of hospitals and other community resource centres. Educating nurses to better understand resources outside their own area of practice can facilitate their ability to help individuals and families enter into the services they need.

Implications for Policy

While Ontario’s Ministry of Health and Long-Term Care (2009) proposed strategies to integrate people into the mental health care system appropriately, parents describe experiencing a number of the same challenges today that were identified almost a decade ago. Strategies proposed to transform the health care system need to have specific and measureable outcomes attached. Further, investments in research programs that measure their effectiveness should be included in such strategies. Nurses, who work in a number of health care settings in which mental health care is provided, could advocate for and lead such initiatives. Policies that enable advance practice nurses and Nurse Practitioners to practice at full scope can improve community mental health care delivery, especially in rural and remote communities.

Additionally, nurses can shape policy changes through their involvement in professional organizations and using those channels to draw attention to, and advocate for, family-centred policies and practices. Nurses can conduct research, learn how practice change takes place, and find ways to translate knowledge into practice. Being the largest health care profession, and working within an evidenced-based practice, changes in nursing can have a ripple effect on changes in the health care system as a whole.

Implications for Education

The Canadian Association of Schools of Nursing (CASN) recently defined entry-to-practice mental health and addiction competencies for undergraduate nursing education (CASN, 2015). According to CASN, nurses entering practice are expected to promote recovery while developing a plan of care in collaboration with individuals, their families, and the health care team. However, university courses continue to overemphasize a biomedical model of care centred upon illness with only some integration of a more holistic perspective (Eggenberger & Regan, 2010). Understanding the roles, challenges, and experiences of families is an important component of family centred care. This is not a one-size-fits-all approach, as the findings of this research emphasize specific considerations for parents caring for an ACWS, for example.

In their clinical placements, it is rare that nursing students have the opportunity to sit in on team meetings with families, especially within the mental health care setting. As a result, new graduate nurses enter practice with little or no experience of working with these families. Parents caring for ACWS have with complex needs. Students need greater exposure to families while in their clinical placements so that they are better prepared to be effective family health care providers.

Implications for Research

To better address caregiver psychological distress, researchers should embark on the creation of theoretically-driven interventions specific for parent caregivers of ACWS. This would allow clinicians to better support these individuals in a consistent, evidence-informed manner. Further, such theories could form the basis for caregiver support programs. At present, these programs operate without a specific underlying theory or model, and are delivered inconsistently across health care and social settings. Evidence-informed programs should be adopted, where appropriate, so that knowledge can be translated and provided consistently across settings and care providers. There are no consistent processes and yet we see patterns in the experiences of parent caregivers which offers possible avenues for improving care based on evidence. However, evidence-informed programs must be balanced with individual needs and situated within a patient and family-centered care approach. If the psychological wellbeing of caregivers is not addressed appropriately, caregivers may burnout and develop (or worsen an existing) psychiatric illness. This would lead to adverse health, social, and economic consequences for the caregiver, ACWS, family, the healthcare system, and for society.

Parents included in both studies expressed concerns about what would happen to their children once they died. Lifetime Networks (a program of Citizen Advocacy) is a program created for and by families who have a relative with a disability (including schizophrenia) and facilitates the establishment of a caring personal support network for these persons. Very little research exists to demonstrate the effectiveness of these programs, but anecdotally, I have had patients and families (both in research and clinical practice) emphasize how helpful and wonderful these programs are. Further research is necessary to underpin the increased use of these programs.

To address problems with access, availability, and appropriateness of resources, future researchers might consider a review of interventions that limit fragmentation and improve navigation and access in the mental health care system. By reviewing existing interventions for effectiveness, meaningfulness, and cost, decision makers will be able to draw upon evidence and implement the best possible strategies in their settings.

Finally, the parents included in these two studies reflected deeply on their experiences at the time of illness onset. This time in their lives was fraught with chaos and distress. Several parents remarked that it would have been difficult, if not impossible, to participate in research during that period. Exploring the needs of parent caregivers longitudinally, from first psychotic episode through to recovery, would provide better insight into particular needs during each pivotal time in the illness trajectory. Engaging families in research at the onset of schizophrenia would likely be difficult, and thus researchers should begin by exploring strategies to promote recruitment and retention. This might be enhanced through using a participatory action approach, where the participants themselves are active members of the research team and research questions are driven by them.

Concluding Statements

The findings of this thesis contribute to our understanding of how parents experience their role as caregiver for their ACWS. Health care providers, policy-makers, educators, and researchers must work collaboratively to improve families' abilities to navigate the mental health care terrain. This is especially problematic at the time of illness onset and during times of illness exacerbation. Difficulties with access, availability, and appropriateness of resources further compounded the psychological distress already experienced by these caregivers. Parent caregivers are frequently cited as indispensable resources within the health care system; however, the support they provide to their ACWS often comes at an enormous cost to their own well-being. Health care providers must understand, acknowledge, and address these caregivers' needs while reforming the mental health care system so that caregivers can remain healthy, empowered, and more satisfied in their caregiving roles.

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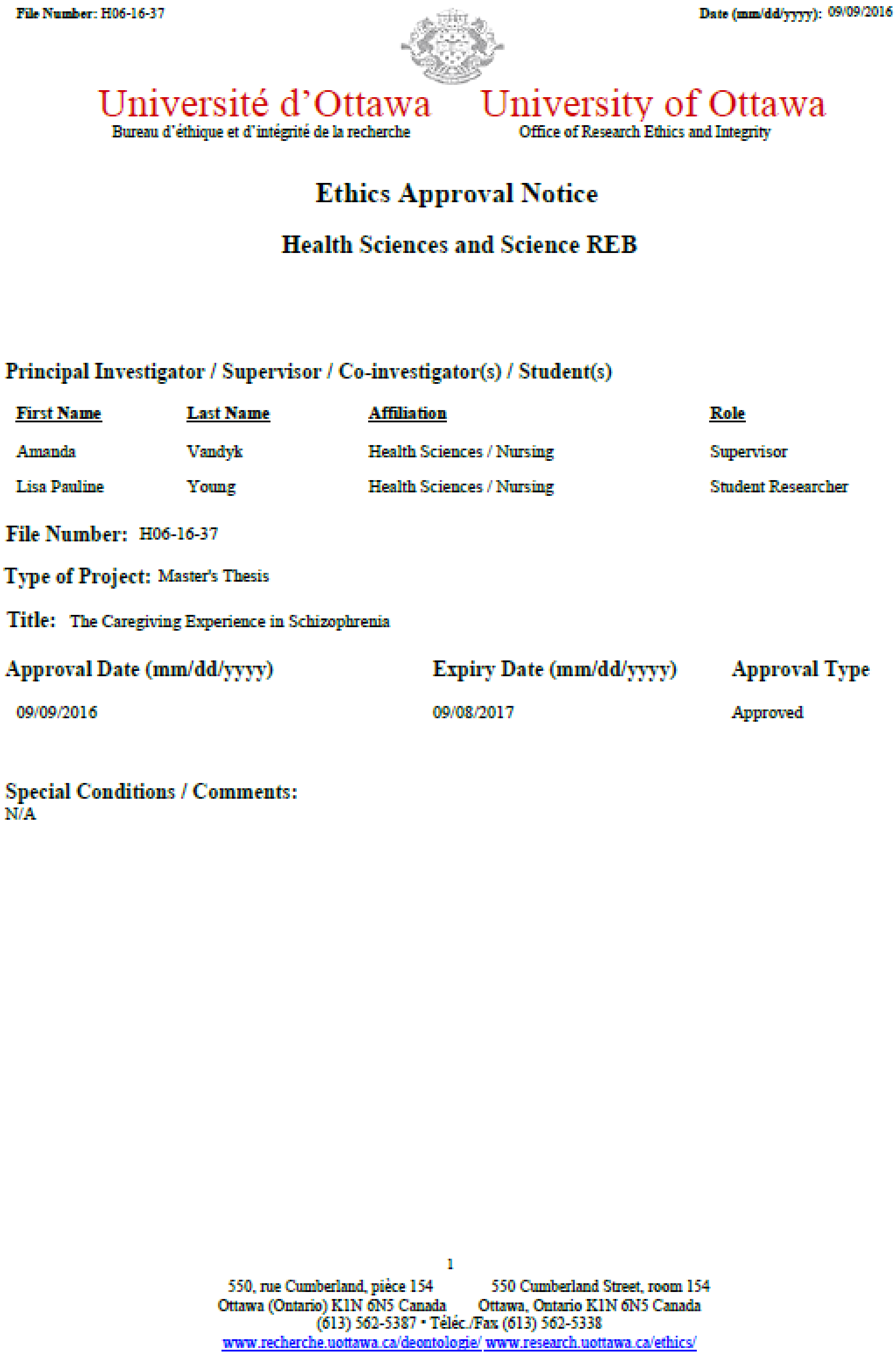
Appendix A – Ethics Approval



File Number: H06-16-37 **Date (mm/dd/yyyy):** 09/09/2016

Université d'Ottawa University of Ottawa
Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

Ethics Approval Notice

Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

First Name	Last Name	Affiliation	Role
Amanda	Vandyk	Health Sciences / Nursing	Supervisor
Lisa Pauline	Young	Health Sciences / Nursing	Student Researcher

File Number: H06-16-37

Type of Project: Master's Thesis

Title: The Caregiving Experience in Schizophrenia

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
09/09/2016	09/08/2017	Approved

Special Conditions / Comments:
N/A

Appendix B – Qualitative Study: Study Information and Consent Form

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Université d'Ottawa
Faculté des sciences
de la santé
École des sciences
infirmières
University of Ottawa
Faculty of Health
Sciences
School of Nursing

☎ 613 562-5473
613 562-5443
451 Smyth
Ottawa ON K1H 8M5 Canada
www.uOttawa.ca

PARTICIPANT INFORMED CONSENT FORM

Participation in this study is voluntary. Please read this Participant Informed Consent Form carefully before you decide if you would like to participate. Ask the researcher as many questions as you like.

Title of the study: Caregiving experience in schizophrenia

Lisa Young, RN, BScN
Master of Science in Nursing Student
School of Nursing, Faculty of Health Sciences
University of Ottawa - Roger Guindon Hall

Amanda Vandyk, RN, Ph.D.
Thesis Supervisor and Professor
School of Nursing, Faculty of Health Sciences
University of Ottawa - Roger Guindon Hall

Invitation to Participate: I am invited to participate in the abovementioned research study conducted by Lisa Young and supervised by Dr. Amanda Vandyk. This research study is a required component of Lisa Young's Master of Science in Nursing Program.

Purpose of the Study: The purpose of the study is to explore the experience of parents caring for their adult children with schizophrenia. It is important the caregivers' voices are heard so that family-centered perspectives in health and community care can continue to be improved.

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de la santé

École des sciences
infirmières

University of Ottawa
Faculty of Health
Sciences

School of Nursing

Participation: My participation will consist of completing a brief sociodemographic questionnaire and a tape-recorded interview of approximately one hour duration with Lisa Young. I will be asked questions about my experiences as a caregiver of an adult child with schizophrenia. I will be asked things, such as, "Tell me a bit about your experience as a caregiver" or, "tell me about your experiences with the health care system." My preference for time and location of the interview will try to be accommodated as much as possible. Should I prefer a public location, I recognize that complete confidentiality cannot be ensured, though attempts to increase privacy (i.e. a more private table or location) will be made. I can take breaks at any point in the interview and can skip over any questions I prefer not to answer.

Risks: My participation in this study will entail that I volunteer personal information. This might cause me to feel emotional or psychological distress. I have received assurance from the researcher that every effort will be made to minimize these risks, including debriefing and being offered a card containing the Crisis Line phone number.

Benefits: My participation in this study will help to contribute to our current understanding of what it's like for parents to care for their adult child with schizophrenia. The knowledge gained has the potential to influence future research and mental health care interventions for families and caregivers providing care to people with schizophrenia.

Confidentiality and anonymity: I have received assurance from the researcher that the information I will share will remain strictly confidential. I understand that the contents will be used only for the purposes of this study and that my confidentiality will be protected. Measures to protect confidentiality include encryption of the tape recorder used in interviews. A code number will be assigned to my information, and this information will be stored in Dr. Amanda Vandyk's locked filing cabinet in a locked office at the University of Ottawa. Only the researcher and supervisor named in this consent form will have access to my information.

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infirmières

University of Ottawa
Faculty of Health
Sciences
School of Nursing

The link between my unique study number and your name and contact information will be stored securely and separate from my study records, and will not leave the University of Ottawa. Any documents or samples leaving the University of Ottawa will contain only your unique study number. This includes publications or presentations resulting from this study.

Information that identifies me will be released only if it is required by law. In the event that I disclose information that indicates an imminent risk of harm to myself or others, for example that there is imminent risk of suicide, homicide, self-harm, or harm to others including physical or sexual assault, I understand confidentiality must be breached.

For audit purposes only, my original study records may be reviewed under the supervision of Lisa Young by representatives from the University of Ottawa Research Ethics Board.

Anonymity will be protected through encryption of the tape recorded information. Only the researchers named in this consent form will have access to listening to the tapes and typing the interviews on a computer. My identity will not be shared with anyone else, and will not be revealed in publications. Anonymous quotes taken from interviews may be used but unique identifying information would not be revealed.

Conservation of data: My data will be conserved on the University of Ottawa campus for 10 years and then destroyed. Paper will be shredded into pieces in a shredder. Electronic data will be erased from the encrypted key.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences. Choosing to participate or not participate does not affect the standard of health care provided to myself, family, or adult child. If I choose to withdraw, all data gathered until the time of withdrawal will be destroyed.

Compensation: I understand that costs associated with transportation will be reimbursed and I will be a given a gift card valued at $20.00 for my time. Even if I choose to withdraw from the study, I will be provided with the full compensation amount provided I have given my consent.

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Transcript Review: I will have the opportunity to review my interview transcript. I can contact Lisa Young by email and can review transcripts before the conclusion of the study.

Acceptance: I, ________________________ have read the above consent form and any questions I had have been answered to my satisfaction. I agree to participate in the above research study conducted by Lisa Young of the School of Nursing, Faculty of Health Sciences, University of Ottawa. This research is under the supervision of Dr. Amanda Vandyk.

If I have any questions about the study, I may contact the researcher or her supervisor. If I have any questions regarding the ethical conduct of this study, I may contact:

The Protocol Officer for Ethics in Research
University of Ottawa - Tabaret Hall,
550 Cumberland Street, Room 154,
Ottawa, ON
K1N 6N5
Tel.: (613) 562-5387
Email: ethics@uottawa.ca

There are two copies of this form, one of which is mine to keep.

____

Participant Name

____

Participant Signature

____

Date

____

Researcher's Name

____

Researcher's Signature

____

Date

Appendix C – Qualitative Study: Recruitment Poster

uOttawa
L'Université canadienne
Canada's university

Title of the study: Caregiving experience in schizophrenia

Are you a parent of an adult child with a diagnosis of schizophrenia?

Are you interested in sharing your experience in order to inform research and, potentially, health care practices?

WHO:	Are you the primary caregiver for an adult child with schizophrenia or schizoaffective disorder?
WHAT:	I'd like to talk to you about your experience.
WHEN:	At a time convenient to you.
WHERE:	At a private place that works best for you.

I am hoping to recruit up to 12 caregivers. Eligible participants will be selected on a first come first served basis.

Your personal information and participation would be treated confidentially in accordance with requirements set out by the University of Ottawa Research Ethics Board.

This research is being conducted as part of my Master of Science in Nursing degree and is independent of any organization. Your decision to participate will have no effects on any services you receive.

If you are interested in learning more about this study, please contact me via the information provided below. Thank you!

Researcher:	**Thesis Supervisor:**
Lisa Young, RN, BScN Master of Science in Nursing Student School of Nursing, Faculty of Health Sciences University of Ottawa - Roger Guindon Hall	Amanda Vandyk, RN, Ph.D. Thesis Supervisor and Professor School of Nursing, Faculty of Health Sciences, University of Ottawa - Roger Guindon Hall

Appendix D – Qualitative Study: Recruitment Script

Hello,

Thank you for taking the time to speak with me. My name is Lisa Young and I am a Master of Science in Nursing Student working with my thesis supervisor Amanda Vandyk from the University of Ottawa. I am calling to ask if you are interested in participating in a research study. Thank you for your interest..

I am hoping to speak to people, like you, who have experience caregiving for an adult child with a diagnosis of schizophrenia. My goal is to understand, from your experience, what this is like. I hope that by understanding your experience, better care might be provided for caregivers like yourself, or for other families like your own, in the future.

Would you like to speak to me about this? I am happy to answer any questions that you might have.

If ‘**no**’: Thank you for your time. If you change your mind or want more information, I can be reached anytime by email (provided in original) or you could also contact my thesis supervisor, Amanda Vandyk at (provided in original)

If ‘**need more information**’: I am happy to answer any questions. Where should we start?

If ‘**yes**’: Wonderful! Let’s start by noting that your participation in this study is voluntary. If you decide to participate, you have the right to withdraw consent at any point without affecting your current or future medical care or other services to which you are entitled or are presently receiving. Let me explain further details of our study now! If you choose to participate, you will meet with me at a location of your choice to discuss the study in detail, sign an informed consent form, complete a questionnaire and participate in an interview where we will discuss your experiences as a caregiver. This visit should take about one hour. Please note that this interview will be audio-recorded.

Does this study sound like something you would be interested in participating in?

If ‘**no**’: Thank you for your time.

If ‘**need more information**’: That’s completely understandable. Do you have any questions that I can answer, or is there anything else that you would like me to clarify?

> **Yes** – answer questions/give clarification
>
> **No** – No problem! If you would like to think about it, I could give you a call back. Is there a convenient time in the next few days for me to call you to discuss it further? (**arrange Date and Time**)

If ‘**yes**’: Wonderful! I am very happy that you are willing to speak with us further.

Proceed with Booking Visit - We will now proceed with booking your visit. I am happy to meet you at a private location of your choice, where we can speak and go over the Consent Form. When are you available? Great!

You may email me or can email or call my thesis supervisor, Amanda Vandyk at any time if you have any questions about the study. Or, if you want to meet or speak with me or Amanda Vandyk before making a decision about participating, we will arrange that as well. Do you have any questions for me at this time? Thank you so much for your time today, we'll see you soon!

Appendix E – Qualitative Study: Interview Guide

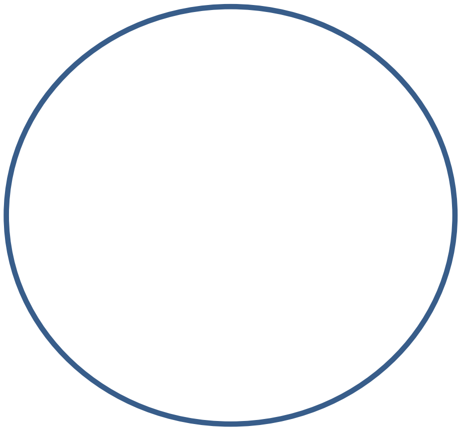
1) Tell me a bit about your experience as a caregiver.
    a. Possible probes:
        - First diagnosed
        - Past
        - Present
        - Future
            - What would be of help in the future? Services? How do you get there?
2) How did you become the primary caregiver?
3) What are the best things about being a caregiver?
4) What are some of the challenges you face as a caregiver?
5) Talk to me about your supports?
    a. Possible probes:
    - Talk to me about the supports you have
    - Talk to me about the supports of your child
    - Formal and informal supports
    - Describe how much of the support is given by you by explaining it.
        - Option to interpret this through drawing it on pie shaped paper.
6) Can you tell me about what it's been like working with the health care system?
    a. Possible probes:
        - Mental health care system
        - Access
        - Costs
        - Do you feel your voice has been heard as a member of the health care team?
7) Is there anything else you'd like to tell me?

Appendix F – Qualitative Study: Sociodemographic Questionnaire

A Bit About Me

<u>Participant ID</u> #: Age: Sex:

- Years spent caregiving:
- Average time spent caregiving per <u>day</u>: per <u>week</u>:



- Other supports (people or organizations) providing care for your child:
- Please circle your highest level of education obtained:

Elementary Some high school High school

Some College or University College or University

Some Graduate Studies (Masters or Ph.D) Graduate Studies (Masters or Ph.D)

(Continued on next page)

A Bit About Me

- Please circle your estimated total household income (Gross):

$0 – $15,000	$15,000 – $30,000	$30,000 – $50,000
$50,000 – $75,000	$75,000 – $100,000	$100,000 – $125,000
$125,000 – $150,000	$150,000 - $175,000	Over $175,000

- Employment Status: Employed / Unemployed
- Are you a caregiver for anyone else?

  If yes, how many others?

  What is the relation?

  Physical or mental illness (or prefer not to disclose)

Family size:

<u>Your adult child:</u>

Age: Sex: Diagnosis:

- Employment Status: Employed / Unemployed
- Does he / she receive income from the Ontario Disability Support Program (ODSP) or Ontario Works (OW)?