

Caregiving and Schizophrenia: The Well Siblings' Perspective

by

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B.A., Mount Allison University, 2006

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Dr. André P. Smith, (Department of Sociology and Centre on Aging)  
**Supervisor**

Dr. Margaret J. Penning, (Department of Sociology and Centre on Aging)  
**Departmental Member**

## **Abstract**

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The purpose of this study was to explore the meanings well siblings attribute to their experiences caring for a brother or sister with schizophrenia. This study retrospectively examined changes in the nature of the relationship between the well and ill siblings before, during, and after the diagnosis of schizophrenia. Ten well sibling caregivers of people with schizophrenia participated in the study. The findings suggest that the sibling relationship was strong in childhood yet weakened in adolescence which influenced the well sibling's caregiving involvement. During the onset of the illness, well siblings spoke about the changes they noticed in their sibling's personality, behaviour, and lifestyle choices and sought professional help. The diagnosis of schizophrenia and the illness resulted in marked changes in the relationship between well and ill siblings. Well siblings spoke about struggling with their ill sibling's dependency and with having to balance their own lives with their caregiving responsibilities.

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**Dedication**

*For Adrienne*

## Chapter 1 : Introduction

### Statement of the Problem

An unintended consequence of the deinstitutionalization of mentally ill beginning in the 1950s is that families have been forced to become the de facto caregivers for their ill relatives (Doll et al., 1976; Grella & Grusky, 1989; Intagliata et al., 1986; Lamb & Oliphant, 1978; Solomon & Marcenko, 1992). In particular, parents of adult children with schizophrenia<sup>1</sup> have assumed greater responsibilities for care provision due to the inadequacy of community-based services (Biegel et al., 1991; Lefley, 1996; Lefley, 1987; Tausig et al., 1992). However, these parents are now aging and their ability to provide long-term care to ill children is decreasing and will eventually end due to disability or death (Lefley, 1987, 1999). When the ability of aging parents is diminished and where community-based services are insufficient, calls for the involvement of well siblings as caregivers is likely to increase dramatically (Friedrich et al., 1999; Lively et al., 1995; Stalberg et al., 2004). Under these circumstances, well siblings maybe poised to take over a larger share of informal care and will eventually be in the position of primary caregivers (Hatfield & Lefley, 2005).<sup>2</sup> With this evolution in the configuration of family caregiving, there is thus a need to further explore the impact on well siblings of looking after a

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<sup>1</sup> The American Psychiatric Association (APA) describes schizophrenia as “a disturbance that lasts for at least 6 months and includes at least 1 month of active-phase symptoms (i.e., two [or more] of the following: delusions, hallucinations, disorganized speech, grossly disorganized or catatonic behaviour, negative symptoms)” (APA, 1994, p. 273). Schizophrenia is characterized by positive symptoms such as hallucinations and negative symptoms such as affective flattening (limited emotional expression), alogia (poverty of speech), and avolition (lack of motivation). In addition, “these signs and symptoms are associated with marked social or occupational dysfunction [e.g., interpersonal relations, work, education, or self-care]” (ibid., p. 274). These criteria must be met for a diagnosis of schizophrenia.

<sup>2</sup> A caregiver can be defined as “an individual, such as a physician, nurse, or social worker, who assists in the identification, prevention, or treatment, of an illness or disability [or;] an individual, such as a parent, foster parent, or head of a household, who attends to the needs of a child or dependent adult”(Dictionary.com, 2010). The key person who generally provides the most care and support to the patient is defined as the “principal [or primary] caregiver” (Awad & Voruganti, 2008, p. 152). For the purposes of this study, I use the term ‘primary caregiver’ to refer to the individual who provides the majority of informal care.

brother or sister with schizophrenia, their current and future expectations as caregivers, and their caregiving experiences.

A deeper exploration of the caregiving experience of siblings is needed as they are increasingly assuming a larger component of care of people with schizophrenia. In particular, suitable research is required to better understand changes in patterns of caregiving among family members in the context of aging parents who are primary caregivers. This study is relevant for the Canadian mental health system as it will inform mental health professionals about siblings' caregiving experiences and facilitate the development of sibling-orientated support services which are currently scarce and insufficient (Landeem et al., 1992; Lukens et al., 2004). This study will also help other siblings and families learn more about their caregiving experience and schizophrenia as well as other chronic disorders. In addition, by exploring the sibling experience, it will expand our understanding of the similarities and differences among family caregivers of people with schizophrenia.

### **The Research Questions**

The primary research questions for this study are:

- (1) How do well siblings relate to the brother or sister with schizophrenia; and how has this relationship<sup>3</sup> evolved before and since the onset of the illness?
- (2) How do well siblings understand the meaning of the term caregiving; and what kinds of activities do they consider as caregiving activities?

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<sup>3</sup> Cicirelli (1995) defines sibling relationships as the “total of the interactions (physical, verbal, and nonverbal communication) of two or more individuals who share knowledge, perceptions, attitudes, beliefs, and feelings regarding each other, from the time that one sibling becomes aware of the other” (p. 4). The discernable characteristics of sibling relationships is “the interdependency of two children in a family who either (1) share some degree of common biological origin (full siblings, half-siblings); (2) share a relationship defined legally (stepsiblings, adoptive siblings); or (3) share some degree of commitment or socialization to the norms of sibling roles in a particular culture (fictive siblings)” (ibid.).

- (3) In what way are well siblings currently involved in caregiving; and how does this compare to the care their parents provide?
- (4) What responsibilities do well siblings feel they have in relation to the affected brother or sister; and how do they believe those responsibilities will evolve as parents age?

### **Theoretical Framework**

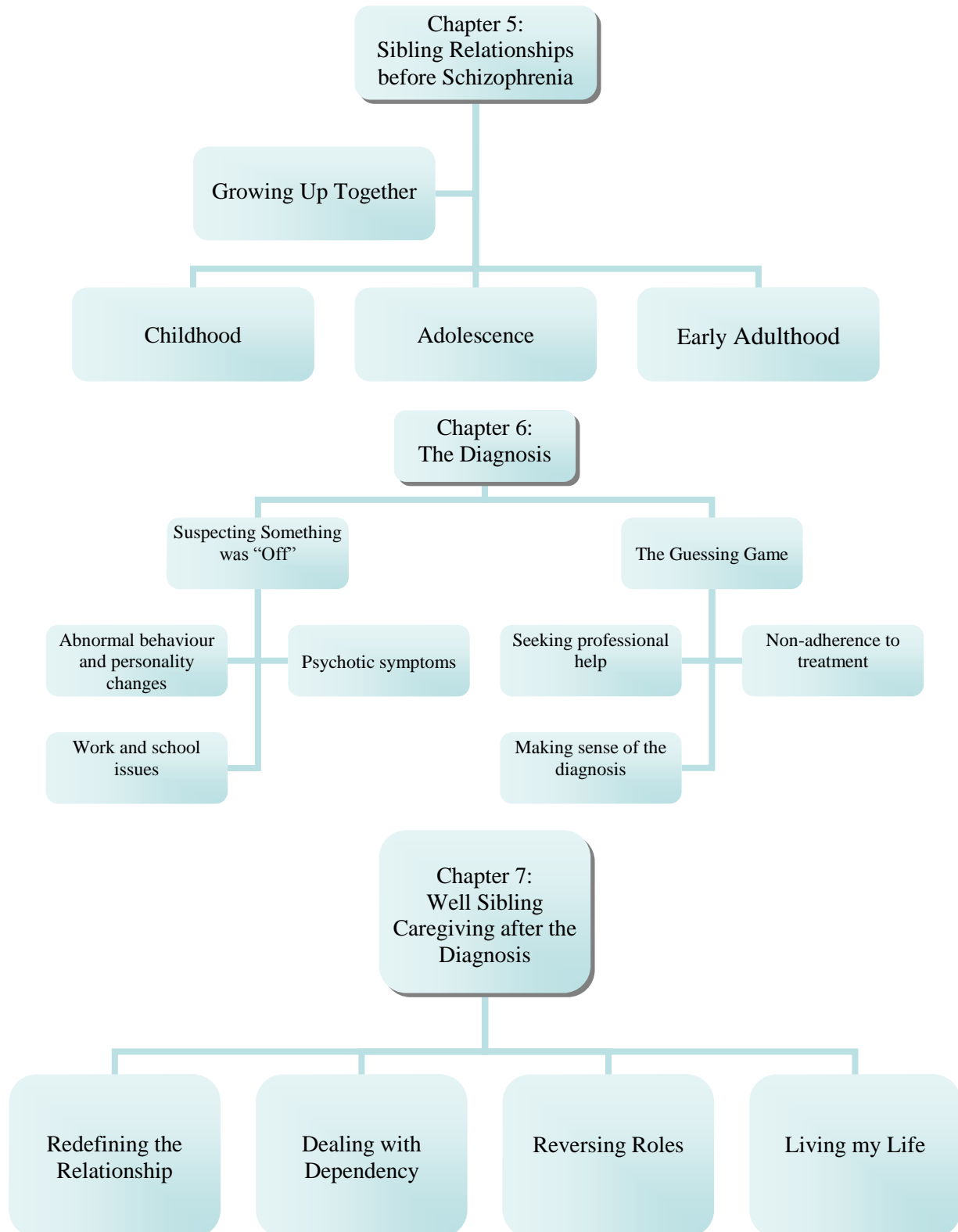
In this study, I adopt a symbolic interactionist framework to help understand the evolution of the caregiving relationship between well and ill siblings. This study conceives of caregiving as a social process that is influenced by how well siblings reconstruct the affected brother's or sister's identity and condition along medicalized lines (i.e., as someone with a chronic illness). The framework is particularly appropriate for this study, which seeks to situate well siblings' experiences caring for a brother or sister with schizophrenia in the contexts of their daily lives. More specifically, I incorporate elements from Goffman's (1961, 1963) ethnographic work on stigma, and Scheff's (1966, 1967, 1975) labelling theory. Goffman's and Scheff's theoretical insights are helpful in guiding this examination on how siblings define their relationships with their affected brothers or sisters and of the process of becoming a caregiver.

### **Overview of the Thesis**

The thesis is comprised of eight chapters. **Chapter Two** reviews literature on sibling caregiving, schizophrenia, and caregiver burden. **Chapter Three** details the study's data collection, analysis procedures, and ethical considerations. The findings section is composed of four chapters. **Chapter Four** provides a detailed description of the participants and their ill siblings. Chapters five, six, and seven report on the experiences of the well siblings before, during, and after the diagnosis of schizophrenia (see Table 1 for a visual representation of the

major themes and sub-categories from the findings for each of these chapters). **Chapter Five** describes the maturation process of the well siblings and how the nature of their relationship evolved up until the diagnosis. I further address the implications of the state of the sibling bond prior to schizophrenia and its effect on the current caregiving relationship. **Chapter Six** explores how the well siblings felt about the early symptoms and diagnosis of schizophrenia and their experiences with the changes observed in their sibling's personality, behaviour, and life style. It also describes changes in this period in the relationship between well and ill siblings. **Chapter Seven** discusses how the illness impacted the way well siblings related to their affected brother or sister. I end by distinguishing between parental and sibling care and discussing well siblings' expectations of future caregiving. **Chapter Eight** gives a summary of the findings, strengths, and limitations of the study, and implications for future research and mental health-care delivery.

**Table 1: Thematic Diagram**



## Chapter 2 : Literature Review

This chapter reviews literature on how the caregiving role of families has evolved since deinstitutionalization and on changes in the mental health system that have created the conditions in which families have increasingly assumed the major responsibilities for the care of people with schizophrenia. This chapter also discusses the demographic shifts (i.e., population aging) that are positioning well siblings to increasingly become primary caregivers to ill siblings. I also review literature on caregiver burden and the future involvement by siblings. I demonstrate that most studies document the negative effects of schizophrenia (e.g., amount of instrumental and emotional burden) on well siblings and argue for the need to better articulate the meaning of caring for a brother or sister with schizophrenia over the life course.

### Family Caregiving and Schizophrenia

This section describes the restructuring of the mental health system that resulted in a transfer of care onto the families of people with schizophrenia. Recent literature reviews indicate that family members of people with a severe mental illness (SMI)<sup>4</sup> have high levels of caregiver burden<sup>5</sup> due to a number of factors, such as the severity of symptoms. This literature outlines how these caregivers adopt various coping strategies to deal with the lack of social support they receive from formal caregivers (e.g., mental health professionals) (Greenberg et al., 2000; Seltzer

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<sup>4</sup> SMI is considered a category of disorders more debilitating than other forms of mental illness. SMI is “defined through diagnosis, disability, and duration, and includes disorders with psychotic symptoms such as schizophrenia, schizoaffective disorder, manic depressive disorder, autism, as well as severe forms of other disorders such as major depression, panic disorder, and obsessive compulsive disorder” (United States Senate National Advisory Mental Health Council, 1993 as cited in Earl, 2006, p. 52). Schizophrenia is the most common diagnostic category affiliated with SMI.

<sup>5</sup> The term ‘caregiver burden’ has been criticized frequently for being too broad, as well as for possessing a mostly negative connotation with respect to its impact and consequences on the caregiver. As family members have reported positive aspects of caregiving, alternative terms have been proposed—such as ‘experience of caregiving’—to replace this traditional term. “Nevertheless, burden of care continues to be the most frequently used concept, reflecting the extensive negative impacts of burden of care as documented in the extensive literature” (Awad & Voruganti, 2008, p. 154).

et al., 1995). Caregivers are disrupted in most areas of their lives—including work and relationships—experience stigma, and report psychosocial interventions (e.g., self-help support groups) as a significant alleviator of stress and need for family caregivers (Awad & Voruganti, 2008; Baronet, 1999; Brady & McCain, 2004; Loukissa, 1995; Saunders, 2003; Teschinsky, 2000).

The importance of family caregiving has become more recognized since the mid-1950s when a growing number of patients were discharged from psychiatric hospitals and placed into the community.<sup>6</sup> Today, the vast majority of people with schizophrenia live in the community, not in psychiatric hospitals (Lamb & Bachrach, 2001). Torrey (2001) estimates that almost 90% of people with schizophrenia in the U.S., who are living in communities today, would have been institutionalized 45 years ago. For example, Riverview Psychiatric Hospital in British Columbia was reduced in size from approximately 4,000 patients to 850 between 1959 and 1994 (Ombudsman, Province of British Columbia, 1994). In a provincial report (*ibid.*) of Riverview in 1994, it was projected the hospital would become a 300 bed tertiary care facility by the year 2000. In a 2010 update by the Ministry of Health Services (2010) reported having opened 441 beds across the province with 402 more beds being finalized to be developed within regional facilities to accommodate the transfer of patients from Riverview.

Once in the community, people with severe forms of schizophrenia are highly dependent and require extensive caregiving to replace the care previously provided by psychiatric hospitals. Community care typically involves a combination of formal systems of care and informal

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<sup>6</sup> The deinstitutionalization of mental health services and populations in Canada fundamentally consists of three processes: discharge and divert patients with SMI from psychiatric hospitals into alternative facilities in the community; increase the amount of mental health beds or psychiatric units in general hospitals (transinstitutionalization); and develop community-based services to substitute for psychiatric hospitals that traditionally provided long-term care and treatment for the severe mentally ill populations (Sealy & Whitehead, 2004).

support networks, such as the family (Tausig et al., 1992).<sup>7</sup> Although there is acknowledgement of the value of involving families in community care (Riebschleger, 2002; VMHS, 2004), this seldom happens. Yet, including families would seem useful in an era of resource constraints in mental health practice (Lefley, 1996).

An unintended consequence of deinstitutionalization is that families have been forced to become the de facto ‘case managers’ for their ill relatives (Doll et al., 1976; Grella & Grusky, 1989; Intagliata et al., 1986; Lamb & Oliphant, 1978; Solomon & Marcenko, 1992). Family members are the most common source of social support for people with schizophrenia (Pernice-Duca, 2008). Around two thirds of people with schizophrenia in Canada reside with their families at any given time (Seeman, 1988 as cited in Lefley, 1996). The National Alliance for the Mentally Ill (NAMI) reports that 42% of people with SMI in the US live with a family member, primarily a parent (Torrey, 2001). Lefley (1987, 1996) estimates that 35% to 40% of people with SMI reside with their families. Since most people with schizophrenia do not reside in psychiatric hospitals or acute psychiatric care in general hospitals for long periods of time, close family members essentially provide many aspects of daily care. In most cases, more than one family member is involved, including fathers, siblings, and especially mothers (Bowman et al., 1989 as cited in Tausig et al., 1992).

Without this informal system of care, people with schizophrenia rely on fragmented community-based services (Lukens et al., 2004; Mechanic, 1998).

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<sup>7</sup> The literature on informal or non-institutional systems of care refers to ‘informal care’ as providing emotional or instrumental support to a recipient in which the caregiving relationship is typically characterized by intimate or obligatory social relations based on strong particularistic ties (Horwitz et al., 1992). Pearlin and colleagues broadly define informal caregiving as “activities and experiences involved in providing help and assistance to relatives or friends who are unable to provide for themselves” (1990, p. 583 as cited in Hunt, 2003, p. 28), rather than formal systems of care, such as community-based services, which are generally structured around institutional processes or avenues of care.

In Canada, there has been a gradual development of community-based services (Sealy & Whitehead, 2004). But these community-based services have been inadequate to ensure a successful integration of people with SMI without assistance from informal networks. For example, families continue to assume the majority of the residential care of people with schizophrenia (Biegel et al., 1991; Lefley, 1996; Torrey, 2001). Carter and Nutt (1998) call family caregivers “a valuable and often invisible part of our health care system” (p. 1245). Families are required to become experts as they learn how to navigate the mental health system.

### **Aging Parental Caregivers and Schizophrenia**

As people with schizophrenia grow older in the community, so do their caregiving parents. Canada’s population is aging (Moore & Pacey, 2004). According to Statistics Canada (2006), one out of three Canadians was a baby boomer in 2006 (born between 1946 and 1965). Thus, a growing number of parental caregivers of people with schizophrenia are now entering the later stages of their lives (Lefley & Hatfield, 1999). Lefley (1987) reports that 85% or more of caregivers of discharged patients with SMI were older parents, most of whom were in their late 50s and 60s (Hatfield, 1983; Swan & Lavitt, 1986; Williams et al., 1986 as cited in Lefley, 1987, p. 1063). Similarly, a US community survey of 697 caregivers of people with schizophrenia found that 70% of mothers were 60 years of age or older and 33% were over 70 years old (Awad & Wallace, 1999 as cited in Awad & Voruganti, 2008, p. 153). Over time, these aging parents’ capacity to provide care will diminish and eventually end due to declining abilities and health problems (Lefley, 1987; Lefley & Hatfield, 1999).

There is a dearth of research on the troubles and issues experienced by aging parental caregivers of people with SMI. Studies that compare the parents of SMI with developmentally disabled people report that aging parents of people with SMI experience greater caregiver

burden, indicate higher levels of family disruption and conflict, have fewer available support systems, and report fewer resources among providers of care to substitute for their caregiving role in the future than parents of people with mental retardation (Greenberg et al., 1993, 1997b; Ha et al., 2008; Lefley & Hatfield, 1999; Pruchno et al., 1996; Seltzer et al., 1995, 1997b). Aging caregivers experience similar concerns and anxieties regarding 'when I am gone' and the future of their mentally ill offspring (Cook et al., 1994, 1997; Lefley & Hatfield, 1999).<sup>8</sup> The worry of planning for future care is exacerbated by the lack of community-based services and makes this issue a central one for families. Seventy-four percent of participants in a survey of NAMI families voiced fear of 'what will happen to my relative when I am gone' as the greatest source of distress (NAMI, 1993 as cited in Lefley & Hatfield, 1999, p. 372).

A consistent result across studies reveals that only 10 to 20% of elderly caregivers have made plans about future living arrangements for their ill relatives (Hatfield & Lefley, 2000; Smith, 2004). Most reported turning to their other children (i.e., well siblings) to assist with planning and found them helpful. Few aging parents reported turning to mental health professionals and advocacy groups such as NAMI (Hatfield & Lefley, 2000). Some aging parents delay planning for so long that they become too frail to address the issue. Several investigators have observed that the demands of caregiving over many years discourage families from planning for the future without professional assistance and urging (Rimmerman, 1996 as cited in Lefley & Hatfield, 1999, p. 371). Many barriers, such as a lack of information regarding how to plan, their interdependency with their offspring, or limited finances (ibid.), also hinder parents from making definite plans.

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<sup>8</sup> Other commonalities among the experiences of aging parents of people with SMI and mental retardation include: the caregiving tasks they perform for their child in areas such as hygiene, monitoring medication, and transportation; and coping with the feelings of loss and mourning that arise from the realization that their child will not lead a 'normal' life. For more information on the similarities and differences of these groups, see Greenberg et al., 1993.

Without adequate future planning for when aging parents are unable to sustain this burdensome role, there will be a serious social problem (Lefley, 1987). If friends or relatives do not assume the caregiving role, community-based services may be overburdened. Ill offspring who outlive their parents may be unsuitably placed in an unprepared and overwhelmed service system (Smith, 2004). Little attention has also been given by mental health professionals to preparing people with schizophrenia for the increasing deterioration and eventual death of their parental caregiver(s). Jones and associates (2003) discovered that people with SMI who co-reside with a parent experience significant and long-term grief after the death of a mother or father. As well, this lack of future care planning creates sudden changes in lifestyle, residence, and finances for people with SMI.

Studies indicate that aging parents, particularly older mothers, prefer the caregiving responsibility to transfer to well sibling(s) of the ill brother or sister (Pruchno et al., 1996; Smith et al., 2000). Instead of looking to other relatives who are elderly, aging parents will frequently count on younger family members who have the ability, resources, and are willing to provide care (Lefley, 1987). Smith and colleagues (2000) note that 76% of the mothers in their study, when asked who they would prefer to assume primary caregiving responsibility of their ill family member, indicated siblings. However, only 37% of them felt this would “probably occur,” while 25% felt it would “definitely happen.” The authors highlight the great disparity between parents’ preference for siblings to assume the future caregiving role and the expectation that this will most likely occur. Aging parents often believe siblings are unable to assume this role due to the responsibilities and social obligations in their own lives and thus are hesitant to ask siblings to contribute (Dearth et al., 1986 as cited in Lefley, 1987).

This is problematic because future plans for the care of ill offspring should be made well ahead of time while aging parents are still alive and able to assist in this transition. The planning process would ultimately be collaborative and involve well siblings and the ill brother or sister (Lefley & Hatfield, 1999; Smith et al., 2000). The care plan should include residential and financial arrangements in conjunction with social support and interaction for daily living (Chen, 2008). Future care planning workshops and psycho-educational support groups for aging parents of people with SMI have proven effective in alleviating apprehension about the future and by providing psychological and practical benefits (Botsford & Rule, 2004; Chen, 2008; Goodman, 2004; Obloy & Hutcheson, 2002).<sup>9</sup>

### **Sibling Involvement in Caregiving**

Researchers argue that siblings will gradually assume a larger share of care for people with schizophrenia (Greenberg et al., 1999; Hatfield & Lefley, 2005; Horwitz, 1993a, 1993b, 1994; Horwitz et al., 1992; Jewell & Stein, 2002; Smith et al., 2007; Smith & Greenberg, 2007, 2008). Siblings are usually not the primary caregivers (Friedrich et al., 2002), but when parents are available to provide support, most siblings play a role in providing informal care (Barnable et al., 2006). Yet, relatively little research has been done on what factors influence involvement of siblings in the care of people with schizophrenia (Jewell & Stein, 2002).

What research evidence is available suggests that sibling caregiving is a product of several factors that either ‘push’ siblings toward the caregiving role or ‘pull’ them away (Greenberg et al., 1999). These factors include parental availability and request, perceived needs

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<sup>9</sup> The Planned Lifetime Assistance Network (PLAN) is one example of a non-profit organization founded by parents that provides future care planning services and long-term support to their loved ones with SMI and other disabilities. This new model of care is designed to ensure the long-term support currently given by parents to their affected child will continue in the future when they are unable to provide such care (Obloy & Hutcheson, 2002).

of the ill brother or sister, geographic proximity, early socialization experiences, severity of the illness, and quality of sibling and family relationships (Greenberg et al., 1999; Hatfield & Lefley, 2005; Horwitz, 1993a, 1993b, 1994; Horwitz et al., 1992; Jewell & Stein, 2002; Marsh et al., 1993b; Smith et al., 2007; Smith & Greenberg, 2007, 2008). Reciprocity between siblings is identified as one of the best predictors of involvement. Siblings report greater levels of care when their ill brother or sister reciprocates through chores, affection, or gifts (Horwitz, 1993a, 1993b, 1994; Horwitz et al., 1996). Newer studies confirm the significance of reciprocity in sibling caregiving involvement (Hatfield & Lefley, 2005; Jewell & Stein, 2002). This finding is also consistent with the wider literature on sibling bonds which highlights the importance of mutual exchange in the sibling relationship.

Research shows siblings increase their involvement in care when other sources of support, especially parents, are unable to do so (Jewell & Stein, 2002; Lohrer et al., 2007). For example, Horwitz (1993a, 1993b, 1994) and associates (1992, 1996) conducted a series of quantitative studies on 108 adult siblings of people with SMI (80% suffered from schizophrenia). These studies looked at the factors that influence siblings' relationships with their ill brother or sister and its impact on social support.<sup>10</sup> Supporting the serial model,<sup>11</sup> siblings provided more contact, intimacy, and care when parents were unavailable. However, most siblings expected to participate in certain ways, such as by helping with daily activities, and not in others, such as by

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<sup>10</sup> “The literature has increasingly presented research in which caregiving is understood as a form of social support” (Earl, 2006, p. 59). Horwitz’s research is one of the first to systematically investigate the possibility of siblings of people with SMI as potential sources of social support (ibid.).

<sup>11</sup> The serial model of social support predicts care is sequentially provided through a ‘hierarchy of obligations’ among the recipient’s social network. When closer relations or kin are unavailable, the next strongest or distant tie will increase their involvement of support. According to this model, if parents are unavailable, siblings will increase their caregiving involvement as they are the next of kin who have the closest ties and obligatory role to the ill relative (Horwitz, 1993a).

keeping appointments. Horwitz (1993a) notes the the types of support siblings often provide, such as emotional support (e.g., gift giving), are not time-consuming or highly demanding.

Rubenstein and associates (2002) determined that as mothers age, the impact of schizophrenia becomes greater on siblings due to the gradual transfer of care from mothers to siblings. Other studies provide evidence of this transfer of care, revealing that the sibling relationship becomes stronger after the death of a parent (Greenberg et al., 1999; Horwitz, 1994; Horwitz et al., 1992). Naturally, parental death can create conflict among siblings (Fuller-Thompson, 2000), which may impact siblings' extent of care to their ill brother or sister. Gender is another factor affecting siblings' current involvement in caregiving. Sisters tend to provide more social support than brothers of people with schizophrenia (Horwitz, et al., 1992; Greenberg et al., 1997a).

Whether or not parents request help from siblings further influences their extent of caregiving involvement. For example, Jewell & Stein (2002) found that many siblings commented that their parents, who had been the primary caregivers for decades, recently requested their help. It is in these instances that siblings felt the most compelled to 'step up' and provide support. This confirms Horwitz's (1993b) finding that sibling involvement in caregiving is more likely to occur when aging parents request assistance. Siblings' reports that parents had begun to ask for their caregiving assistance highlights the urgency and demand for adequate formal and informal support systems.

Although some research has begun to focus on current sibling caregiving, only recently has research been conducted on sibling expectations for future caregiving (Lukens et al., 2004). Caregiver satisfaction and early socialization experiences also impelled siblings toward future involvement, whereas lack of geographic proximity and beliefs about the controllability of

symptoms reduced their willingness to adopt this role in the future (Smith et al., 2007; Smith & Greenberg, 2007, 2008). Greenberg and colleagues (1999) determined that only one third of siblings of people with SMI expect to assume future caregiving responsibility. They reported competing family responsibilities as a major deterrent for the involvement of siblings in caregiving. In reviewing literature on sibling involvement, Horwitz and colleagues (1992) found that “comparative analysis of sibling and parental caregiving indicated that brothers or sisters in their middle years with their own involvements in jobs and nuclear families are unlikely to provide much social support in response to psychiatric disability” (p. 240).

In their survey of 60 siblings, Hatfield and Lefley (2005) found that almost all siblings expected to provide emotional support rather than instrumental support. Siblings reported they would most likely include the ill brother or sister in social gatherings or provide affection. To a lesser extent, though significant, siblings expected to be involved in monitoring medication or managing money. Smith and associates (2007) similarly reported that siblings will provide some form of care, but it seems it will most likely be less extensive care than that from their parents. These findings suggest that while siblings may be a vital source of informal care, they will most likely provide more sporadic care than parents (Stalberg et al., 2004).

This research highlights the multidimensional social processes that influence involvement of siblings as caregivers of people with schizophrenia. Sibling involvement is mediated by complex family processes (Horwitz, 1994; Jewell & Stein, 2002). The extent of care depends upon family history, perceptions, and individual lifestyles and obligations. As such, “service providers should not assume that all siblings are comparable in their capacities and interests as the next generation of caregivers” (Seltzer, 1997a, p. 404). Unless siblings increase their extent of care, become more willing as comparable to their parental caregivers, or professionals

increasingly serve as primary caregivers, there could be a crisis when aging parents are no longer able to provide care to their children with schizophrenia (Horwitz et al., 1992). These findings suggest the need for a study to investigate the processes that mediate siblings' caregiving involvement. The next section examines existing literature on sibling experience and demonstrates how the focus has been on documenting caregiver burden and coping strategies among siblings rather than on the meaning of this experience for siblings.

### **Caregiver Burden, Reward, and Coping Strategies**

Siblings who are involved in the caregiving of a brother or sister with schizophrenia experience significant emotional and instrumental burden<sup>12</sup> because of the chronic nature of this illness (Barnable et al., 2006; Friedrich et al., 2002). Research confirms that the amount of emotional burden experienced by siblings worsens with the severity of the illness and its symptoms (Friedrich et al., 2002; Greenberg et al., 1997a; Lively, et al., 2004; Marsh et al., 1993a; Rubenstein et al., 2002). This is consistent with the broader literature on caregiving and SMI which reveals that the greater the severity of psychotic symptoms, the greater the emotional impact on the caregivers (Awad & Voruganti, 2008; Biegel, 1991).<sup>13</sup> Friedrich and colleagues (1999) report that negative symptoms, such as poor grooming, rather than positive symptoms, were more stressful for well siblings and increased worry and stress. Other studies report that well siblings struggle with feelings such as guilt, anger, shame, jealousy, grief, anxiety, and

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<sup>12</sup> The literature views schizophrenia as a stressor on the family and distinguishes its impact on the family into two manifestations: instrumental (objective) burden and emotional (subjective) burden. Instrumental burden “stems from the mental illness itself [.] It entails the family’s need to deal with the mental health system, financial problems, and the disruption of proper household management” (Barak & Solomon, 2005, p. 234). Emotional burden “consists of the strong feelings that illness evokes, including fear, anger, helplessness, sadness, pain, loss, anxiety, embarrassment and guilt, alongside worry, empathy and identification” (ibid.). More broadly, instrumental burden is the concrete and observable costs to the caregiver due to the illness. Emotional burden is the positive and negative feelings that the caregiver experiences.

<sup>13</sup> Although psychotic symptoms have been found to influence caregiver burden, “there seems to be no agreement on whether a specific cluster of psychotic symptoms has the most impact on caregivers’ burden of care” (Awad & Voruganti, 2008, p. 154). Most studies have found that both positive and negative symptoms are perceived by caregivers to be burdensome (ibid.).

stigma (Denberg, 1996; Lukens et al., 2004; Stalberg et al., 2004; Titelman & Psyk, 1991).

Siblings may feel guilty for their productive lives compared to the turmoil experienced by their ill brother or sister, or experience guilt for being physically healthy, or because they have not done enough to help the caregiving parents (Lefley, 1996).

The emotional burden and developmental problems usually persist throughout siblings' entire lives.<sup>14</sup> Siblings express 'survivor' guilt<sup>15</sup> and conflict about their anger and negative feelings which are projected onto their ill brother or sister. Siblings also report an underlying fear of having 'bad genes' (Stalberg et al., 2004, p. 448–449, 452) and feelings of stigma and shame (Greenberg et al., 1997a; Lukens et al., 2004; Stalberg et al., 2004; Teschinsky, 2000; Titelman & Psyk, 1991). Numerous studies have found similar reports of persistent emotional burden among siblings (Barak & Solomon, 2005; Barnable et al., 2006; Friedrich et al., 1999; Lively et al., 1995; Marsh et al., 1993a, 1993b; Riebschleger, 1991; Samuels & Chase, 1979; Stein & Wemmerus, 2001). Research additionally indicates that siblings incur significant economic costs from providing care to a person with schizophrenia (Lohrer et al., 2007).

Some researchers compare the process that siblings often go through with their brother's or sister's illness with the experience of mourning for a deceased loved one (Karp & Tanarugsachock, 2000; Riebschleger, 1991). For example, Riebschleger (1991) suggests that over time, siblings tend to go through a series of cyclical phases, such as denial, bargaining, anger, depression, and acceptance. However, because of the chronicity of schizophrenia, most siblings are unable to reach the acceptance phase and remain in the grieving process. In a study

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<sup>14</sup> Marsh and colleagues (1993a, 1993b) describe the caregiver burden experienced by siblings that persists after childhood or adolescence and into adulthood as a 'legacy for adulthood' or a 'personal legacy.'

<sup>15</sup> 'Survivor' guilt is broadly referred to in the literature as guilt arising from the fact that siblings who do not become ill subsequently have a more fulfilling, productive, and better QOL in comparison to the compromised QOL of their brother or sister with schizophrenia.

examining how parents and siblings manage their emotions over time, Karp and Tanarugsachock (2000) identified four phases of coping: (1) the initial moment of experiencing the illness (emotional anomie), (2) getting a diagnosis, (3) perceiving illness permanency, and (4) acceptance. Personal accounts by siblings of people with schizophrenia reinforce that siblings experience an emotional burden similar to mourning (Brodoff, 1988; Brown, 1996; Saylor, 1994; Stewart, 2002).

The impact of caring for siblings with schizophrenia permeates most, if not all, aspects of siblings' lives (Chase, 1983; Marsh et al., 1993a) and often persists over their lifetimes. Siblings who experience emotional and instrumental burden are less likely to assume a caregiving role once parents are unable to do so (Seltzer et al., 1997a). However, as Marsh and colleagues (1993b) remark, "there is [thus] a clear need for additional research designed to delineate their experiences more precisely, to explore the legacy of those experiences for their adult lives, and to elucidate their process of coping and adaptation" (p. 14).

The literature on siblings coping with schizophrenia is limited (Friedrich et al., 2008; Gerace et al., 1993; Landeen et al., 1992; Main et al., 1993). Only a few studies have focused on the services and resources that siblings of people with schizophrenia need to cope with the effects of the illness (Friedrich et al., 2008). Within these studies, siblings have been found to develop a number of coping strategies in order to minimize the emotional burden experienced (Barak & Solomon, 2005; Stalberg et al., 2004). At extremes, siblings attempt to 'rescue' the ill brother or sister and become overly involved in caregiving, while others completely disengage from the ill brother or sister and other family members (Denberg, 1996). It is important to recognize that many of the patterns, such as withdrawal from the family, are a means of coping with the intense disruption, and are appropriate responses for these types of social situations

(Torrey, 2001). Siblings implement both constructive and unconstructive coping strategies—from relying on religion (Teschinsky, 2000) and/or seeking therapeutic help to deal with their issues, to engaging in addictive behaviours or repressing emotions (Kinsella et al., 1996).

Gerace and colleagues (1993) outline three unique patterns that encompass siblings' reactions to the illness: (1) collaborative, (2) crisis orientation, and (3) detached phases. The collaborative approach is characterized by constant involvement with the ill brother or sister, family, and mental health professionals. Siblings attempt to incorporate the ill brother or sister into daily routines such as doing laundry. Many siblings' caregiving duties include supporting their parents, who experience a great deal of emotional burden and require comforting (Rubenstein, 2002). In the crisis-oriented approach, siblings' involvement is situation-specific and sporadic. Siblings, in the detached approach, have indirect involvement with the ill brother or sister and sometimes attempt to distance themselves from the family in order to preserve their own lifestyle and well-being. These siblings try to keep the ill brother or sister out of their lives to diminish their sense of responsibility. In all phases, siblings report that their ill brother or sister wields too much power and the parents do not act appropriately in setting proper limits (Gerace et al., 1993).

Stalberg and associates (2004), found similar coping patterns: avoidance, isolation, normalization, grieving, and caregiving. In the normalization coping pattern, siblings psychologically acknowledge the presence of symptoms while minimizing their significance, which is like denial. Consistent with the previous findings, Kinsella and colleagues (1996) describe eight patterns of coping. Barnable and affiliates (2006), in exploring the phenomenology of siblings of people with schizophrenia in Atlantic Canada, identified four

themes: (1) struggling to understand, (2) struggling with the system, (3) caring for the sibling, and (4) seeing beyond the illness.

This literature review shows that research on the experiences of siblings of people with schizophrenia predominately focuses on the negative impact of the illness on siblings. However, siblings also report caregiver reward<sup>16</sup> associated with having grown up with a brother or sister with schizophrenia. The majority of families can identify strengths that they have developed from coping with a relative's SMI (Chen & Greenberg, 2004; Greenberg et al., 2000). Siblings express feelings of love and empathy toward their ill brother or sister, providing a reason for their ongoing support (Stalberg et al., 2004). Other studies report that siblings gain increasing love, sensitivity, and empathy not only toward their ill brother or sister but also to other people who have disabilities (Friedrich et al., 2002; Marsh et al., 1993a).

In dealing with the illness, many siblings become closer to their families and a bond forms that otherwise would not be as strong. Many families pull their resources and responses together in order to effectively provide care (Horwitz et al., 1996; Lukens et al., 2004). Lohrer and colleagues (2002) found that siblings expressed gratification for their ill brother's or sister's small accomplishments, and some siblings felt their lives had been bettered by this experience. Other strengths include: an increase in independence, ability to persevere despite fallbacks, gain of life perspective; re-examination of personal values, resiliency, and decisiveness (Chen & Greenberg, 2004; Greenberg et al., 2000; Kinsella et al., 1996). Although schizophrenia can cause a great deal of caregiver burden, siblings in many occasions collectively bond with the family in times of crises, grow as individuals, and positively reflect on the illness.

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<sup>16</sup> I use the term 'caregiver reward' to refer to the positive aspects of caregiving. Other positive conceptualizations of caregiving that have been proposed and used in the literature include: caregiver esteem, the uplifts of caregiving, gain in the caregiving experience, and making meaning through caregiving (Hunt, 2003).

The following section addresses the gaps evident in current literature. It outlines the research objectives.

### **Gaps in the Literature**

This study addresses several gaps in knowledge in the present literature on the well sibling experience and schizophrenia. Past qualitative studies have elaborated on the experiences of parents, particularly mothers, and spouses caring for an affected loved one (Denberg, 1996; Earl, 2006; Milliken & Northcott, 2003; Smith et al., 2007). However, not many scholars distinguish the experiences and needs of siblings from other family members. Research on the impact and role of caregiving for a brother or sister with SMI on siblings is limited.<sup>17</sup> Moreover, of the studies that examine the impact of SMI on siblings, few concentrate on siblings' experiences with schizophrenia in particular (Barnable et al., 2006).<sup>18</sup>

Some scholars have recognized the need to study the burden of siblings because of the special importance of the sibling bond. Past studies on sibling caregiving and schizophrenia inquired mainly into the socio-demographic factors (such as income, class, and gender) that influenced their levels of burden and extent of social support (Horwitz, 1993; Horwitz & Reinhard, 1995; Horwitz et al., 1996).<sup>19</sup> Only recently has attention been given to attempting to systematically describe the emotional effects of schizophrenia on siblings (Barnable et al., 2006;

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<sup>17</sup> For example, Greenberg et al., 1997, 1999; Hatfield & Lefley, 2005; Horwitz, 1993a, 1993b, 1994; Horwitz et al., 1992; Jewell & Stein, 2002; Lukens et al., 2004; Marsh et al., 1993a, 1993b; Riebschleger, 1991; Seltzer et al., 1997a.

<sup>18</sup> For example, Barak & Solomon, 2005; Barnable et al., 2006; Chase, 1983; Friedrich et al., 1999, 2002; Gerace et al., 1993; Landeen et al., 1992; Lively et al., 1995, 2004; Rubenstein et al., 2002; Smith et al., 2007; Stalberg et al., 2004; Titelman & Psyk, 1991.

<sup>19</sup> Many of the exploratory studies, however, concluded that socio-demographics did not greatly impact the sibling experience. This could be attributed to the limitations of these quantitative studies, such as the relative homogeneity and small size of the samples during this time, which were composed of mostly Caucasians in their middle years. Different findings were discovered when investigations isolated certain socio-demographics to examine more in-depth. For example, Horwitz & Reinhard (1995) found ethnicity impacted sibling caregiving with African Americans assuming more responsibilities, yet reporting these tasks to be less burdensome than their Caucasian counterparts.

Nechmad et al., 2000). Qualitative research has explored such aspects as siblings' involvement and expectations of future caregiving, their response to knowledge concerning the illness, and the impact of the illness on their lifestyles and well-being. Little attention has also been paid to the role of mental health services in assisting sibling caregivers of people with schizophrenia. This is primarily because researchers have traditionally viewed parents as the main sources of social support (Lefley, 1987). Siblings' infrequent and marginal position in their involvement with services further contributes to their disregard among professionals (Denberg, 1996). Another limitation is the lack of recommendations for ways mental health professionals can help reduce the caregiver burden siblings experience (Nechmad et al., 2000).

Until fairly recently, sibling relationships have received the least attention within the family system among researchers (Cicirelli, 1995; Lamb & Sutton-Smith, 1982; Sanders, 2004). This is especially evident when sibling relationships relate to SMI (Denberg, 1996). As Sanders (2004) affirms: "domestic violence and mental illness are examples where there is virtually no literature on sibling *relationships*" (p. 4). The majority of studies are done in the United States and significantly less attention is given by researchers to the experiences of siblings in Canada (e.g., Barnable et al., 2006; Landeen et al., 1992). Most of these studies employ quantitative methods and provide only descriptive accounts (Lukens, et al., 2004). To date, few investigators have used qualitative approaches, particularly in-depth interviewing techniques, to examine the relationship between adult siblings, one of whom is affected by mental illness.

The existing literature on siblings' needs and schizophrenia says that most siblings want parents and professionals to acknowledge the stress siblings undergo in caring for an affected brother or sister (Hatfield & Lefley, 2005). There is often an implicit assumption by mental health professionals that by providing parents with information and support services, the whole

family will have the resources needed to properly cope with illness and deal with caregiver burden (Denberg, 1996). However, as research on sibling caregiving and schizophrenia suggests, this is not the case. It cannot be taken for granted that, by equipping parents with proper caregiving skills and education, the knowledge will necessarily diffuse to siblings (Judge, 1994 as cited in Hatfield & Lefley, 2005, p. 334). While siblings cannot be fully understood without reference to the wider family context (Marsh et al., 1993b), it should not be assumed that siblings necessarily have similar experiences to their parental caregivers. This project attempts to articulate the caregiving experiences of siblings from their perspective in order to compensate for past research on caregiving and SMI that tends to view the family as a unitary system rather than composed of distinct social groups and roles.

Despite the efforts of scholars to define the variables associated with ‘family burden’ in past decades, only recently are attempts being made to systematically delineate the factors associated with the burden experienced by siblings. Some attention has been given to the factors that affect siblings’ adoption of, and psychological and social adjustment to, the primary caregiver role (Denberg, 1996). Notwithstanding this, there are still very few of these investigations and a significant lack of studies that examine specifically siblings’ experiences in-depth. Nechmad and colleagues (2000) identify several limitations in previous research on siblings and schizophrenia, including siblings’ use of the mental health system and their reaction to trauma and loss. In this thesis, I address these issues by exploring the meanings siblings attribute to their experiences caring for a brother or sister with schizophrenia.

### Chapter 3 : Methodology

In this chapter, I provide a summary of the procedures used in the study, including a description of (and rationale for) the adoption of qualitative research methods. I also explain the data collection (sampling, recruitment, and interviews) and analysis (the constant comparative method as outlined in grounded theory) procedures. Ethical considerations when working with sensitive and stigmatized topics and the strategies used to increase the credibility of the study are also discussed.

#### Data Collection

This research project is a qualitative interview-based exploratory study examining the caregiving experiences of well siblings of brothers or sisters with schizophrenia. The purpose of qualitative research is “generally directed at providing an in-depth and interpreted understanding of the social world, by learning about people’s social and material circumstances, their experiences, perspectives and histories” (Snape & Spencer, 2003, p. 22). Qualitative methods were selected because of the study’s focus on participant meaning-making activities, subjective experiences, and interpretations.

**Sampling and recruitment.** Purposive sampling was utilized to identify participants with specific characteristics and experiences that had relevance for this study. Participants were drawn from sibling caregivers of people with schizophrenia in the Greater Vancouver area, British Columbia. In total, ten adult well siblings of people with schizophrenia participated in this study. The ten participants met the following inclusion criteria: (1) have a brother or sister diagnosed with schizophrenia based on the criteria outlined in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) (APA, 1994); (2) have contact with the brother or sister

as evidenced by at least monthly contact via face-to-face interaction, visits, and/or telephone calls<sup>20 21</sup>; (3) be 19 years of age or older<sup>22</sup>; and (4) reside in Greater Vancouver, British Columbia.

Participants were recruited with the assistance of a third party who distributed a recruitment poster (see Appendix A) through an email list that she maintains as part of her activities as an advocate in the field of mental health. This third party is a mother of a child with schizophrenia who has been active in a variety of projects to support families dealing with schizophrenia. She organizes an annual Family Conference in Vancouver; she served on the executive board of the Vancouver/Richmond branch of the BCSS; and was their Branch President. She also served on the Vancouver Community Mental Health Services' Family Advisory Committee. As well, she has written numerous articles on mental illness issues, which have been published in *The Province*, *The Globe and Mail*, and *BC's Mental Health and Addictions Journal*. She is also a published book author on mental illness in the family. The third party was selected because of her advocacy work and her trusted profile within the community of families of people with schizophrenia. She currently oversees a support network for families of people with schizophrenia in the Greater Vancouver area, providing them advice and information through an email list. She agreed to circulate the poster on this email list and indicated support and willingness to follow this recruitment protocol. (For letter of support, see Appendix B.)

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<sup>20</sup> Regular contact and/or experiences with the ill sibling, by virtue of the chronic and debilitating nature of schizophrenia, involves the sibling partaking in some form of caregiving—whether or not they perceive their activities as a form of support, themselves as caregivers, or are the primary or secondary caregivers.

<sup>21</sup> For the purposes of this study, 'caregiving' is broadly defined as emotional and/or instrumental support through a wide range of activities, including supportive conversations, facilitating engagement in recreational activities, monitoring medication, assisting in daily tasks, and so forth.

<sup>22</sup> Adult siblings, 19 years of age and older, were expected to have a certain degree of independence from their families (Samuels & Chase, 1979). However, the age criterion allowed for a wide range of siblings across the life course as well as a diversity of siblings with respect to the course or stage of their brother's or sister's illness trajectory.

The email list has contact information for parents and siblings of people with schizophrenia. People sign up on this list voluntarily and can opt to be removed from the list at any point in time. The third party keeps this list confidential and does not share it with mental health organizations such as the BCSS and/or Vancouver Coastal Health Authorities (VCHA). The recruitment poster provided information on the study, what was expected of the participants, my contact information (cell phone number and email address), and included a request that the participants contact me should they wish to participate or if they wanted additional information about the study.

Upon ethics approval from the Human Research Ethics Board at the University of Victoria, I sent my recruitment poster to the third party for distribution through her email list. She identified suitable siblings to contact from the email list and the recruitment poster was distributed only to siblings on that list. She did not send the poster to siblings who were underage or living outside of Greater Vancouver.

Once participants indicated their willingness to participate in the study, I made arrangements to meet with them for the interview at a location of their choice (e.g., their own residence). Upon discussion, if participants lived with their ill sibling, I recommended that we conduct the interview at a library, recreation center, or my place of residence. I selected the participants on a first-come first-serve basis. There was one person who contacted me after I recruited the needed number of participants. I thanked him for his willingness to participate and let him know that I was no longer able to take on new participants.

**The interviews.** Individual in-depth semi-structured interviews were the main source of data collection because they are “well suited to research that requires an understanding of deeply rooted or delicate phenomena or responses to complex systems, processes, or experiences”

(Ritchie, 2003, p. 36). Interviews also permit detailed examination of individuals' perspectives and personal contexts. The interviews lasted one hour on average<sup>23</sup> and took place at the participants' residence or at their office.

The interview guide (see Appendix C) had questions that centered on the thoughts and feelings of siblings regarding their experiences caregiving for a brother or sister with schizophrenia. Each interview began with obtaining consent from the participants using a written consent form (see Appendix E). I provided an overview of the objectives and purpose of the study verbally, explained what participating in the study entailed, and reviewed the procedures guaranteeing confidentiality and anonymity. Due to the 'sensitive' nature of the research topic and emotional aspects associated in the interview process, I started with non-threatening questions regarding family living arrangements and general caregiver background. This phase enabled participants to become comfortable in the interview setting and with the researcher. Once a rapport was established, I asked broad open-ended questions about these aspects of the participants' experiences to allow the data to emerge freely with the primary aim to develop themes from this data. The interviews focused on the following areas: the participants' relationships with their siblings, their experiences and understanding of caregiving, their understandings and concerns with future caregiving responsibilities, and their experiences with the mental health system.

During each interview, I used the observational protocol suggested by Creswell (2003) and was able to note an array of emotions that were not adequately 'captured' via audio recording and transcription. I also recorded my own reactions and "speculation, feelings,

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<sup>23</sup> Interviews lasting approximately one hour to one hour and a half are typical for this type of interviewing (e.g., Barnable et al., 2006; Gerace et al., 1993; Stalberg et al., 2004). This length of time enabled the siblings to discuss their experiences extensively and in-depth.

problems, ideas, hunches, impressions, and prejudices” (Bogdan & Biklen, 1992 as cited in Creswell, 2003, p. 189). The data gathered from the observational protocol were coded along with the transcribed interviews. Following the interview, I concluded with a debriefing of the study and thanked the participants for their involvement in the study. To preserve the accuracy and richness of the data, the interviews were audio-recorded and transcribed verbatim<sup>24</sup> with permission from the participants. This allowed for a thorough, rigorous, and systematic analysis of the data. The collection and interpretation of the data occurred simultaneously; interview questions were refined on the basis of this preliminary analysis when necessary.

At the beginning of the interview, a demographic questionnaire (see Appendix D) was given to participants to gather information regarding their age, gender, occupation, and living arrangements. This information was collected as a means of describing the participants, their ill sibling, and family, and to provide contextual information about the participants experience caring for their brother or sister with schizophrenia.

I also conducted follow-up interviews lasting 20 to 30 minutes on average at a location and time of the participants’ convenience to verify my analytical accounts of the first interview, to gain further insights into the participants’ experiences, and to inquire about how the participants were doing. I conducted most follow-up interviews over the phone for logistical reasons. Unfortunately, I was unable to conduct follow-up interviews with two of the participants who did not reply.

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<sup>24</sup> The audio recording and transcription of the data was accomplished with the assistance of a Panasonic IC digital recorder model RR-US490. Transcription was done with the use of a voice-editing program.

## Data Analysis

Qualitative analysis is “a process of examining and interpreting data in order to elicit meaning, gain understanding, and develop empirical knowledge” (Corbin & Strauss, 2008, p. 1). Moreover, the analysis “organize[s] and reduce[s] the data gathered into themes or essences, which, in turn, can be fed into descriptions, models, or theories” (Walker & Myrick, 2006, p. 549). In analyzing the data, I followed the principles of grounded theory (GT) as described by Glaser and Strauss (1967).<sup>25</sup> This methodology originated within the interpretive tradition of symbolic interactionism (Charmaz, 2006, p. 28). GT offers “systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories ‘grounded’ in the data themselves” (ibid., p. 2). It is important to emphasize here that this study is not a GT study overall—I only rely on the approach’s key analytic tenets to make sense of the data.

Corbin and Strauss (2008) define coding as “deriving and developing concepts from data” by “using techniques such as asking questions, making comparisons between data, and so on[.]” (p. 65–66). In coding the data, I used memo writing throughout the analysis to “elaborate categories, specify their properties, define relationships between categories and identify gaps” (Charmaz, 2006, p. 6). I also used the following coding procedures: open coding, axial coding, and selective coding. The use of these coding procedures was framed by the principle of the “constant comparative method” (Glaser & Strauss, 1967, p. 101), whereby I collected and interpreted the data simultaneously. I also compared the data across cases and according to various sibling characteristics or experiences (e.g., sibling relationship, early versus late onset of the symptoms).

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<sup>25</sup> GT was developed by sociologists Glaser & Strauss (1967). Since Glaser & Strauss’s collaboration, several scholars have taken GT in divergent directions and have adapted its methods to suit their ontological and epistemological assumptions and approaches. For example, see Charmaz’s (2000, 2006) constructivist approach, Corbin & Strauss’s (1990, 2008) and Glaser’s (2002) objectivist positions (see also Glaser & Strauss, 1967), and Clarke’s (2005) ‘situational analysis.’

In open coding, researchers “immerse themselves in the data through line-by-line analysis, coding the data in as many ways as possible and writing memos about the conceptual and theoretical ideas that emerge during the course of analysis” (Walker & Myrick, 2006, p. 551). During this phase, I broke down the data into codes and labelled these codes according to what they represented, be they ideas, actions, or events. These initial codes were provisional, comparative, and grounded in the data. I then compared the codes for similarities and differences in order to identify and refine the concepts and emergent categories and their dimensions and properties (Charmaz, 2000, 2006).

During axial coding, I reassembled the codes into larger categories and groupings by making connections, patterns, and relationships among the themes and subcategories. I attempted to understand and delineate the relationships between the various themes and categories (Walker & Myrick, 2006) and specified their properties and dimensions. During these processes, I also created a list of my themes, sub-categories, and categories and specified their properties and dimensions (Corbin & Strauss, 2008). This allowed me to discern which ones should be discarded or raised to higher levels of abstraction.

The last phase, selective coding, is the “process of integrating and refining the theory” (Strauss & Corbin, 1990, p. 143 as cited in Corbin & Strauss, 2008, p. 556). Selective coding is similar to axial coding and involves developing larger categories with respect to their properties, dimensions, and connections at a higher level of analytical abstraction (*ibid.*). During this phase, I further dimensionalized key themes and categories by comparing sibling experiences across cases on specific issues (e.g., taking the sibling out, concerns about aging parents).

## **Ethical Considerations**

Several procedures were used to protect anonymity and confidentiality. Many family members of the third party's support network knew each other through common membership and by attending similar BCSS sponsored functions. There is thus a possibility that certain aspects of some siblings' experiences could be identified by other members of the BCSS when reading the final project or hearing a presentation of the results via conference, support group, and so forth. In the consent form, I informed participants that this could occur despite the necessary precautions that were taken regarding confidentiality and anonymity. I also stated in the consent form that it was the responsibility of the participants to decide whether they chose to discuss their participation in this study with the brother or sister with schizophrenia and other family members.

Another ethical concern was that siblings could experience emotional distress in the interview. To prevent this risk, I told the participants that they could request a break to compose themselves; refuse to answer any question; reschedule the interview; or stop the interview altogether, if they experienced emotional distress during the interviews. In addition, if a participant became upset, I offered to debrief with the person or call someone (e.g., a participant's friend or family member) and to stay with the participant until that person arrived. I attached a referral list of available support services in the Greater Vancouver area to the consent form. If participants experienced distress, I explained that they could contact these services for additional counselling, if needed. However, to my knowledge, no participants sought counselling. There were a few occasions where some participants became emotionally distressed. In these instances, all of these participants requested a break to compose themselves but wanted to continue with the interview.

## Credibility

The study used several techniques to ensure the credibility of the data. Creswell & Miller (2000) define credibility in qualitative research as “how accurately the account represents participants’ realities of the social phenomena and is credible to them<sup>26</sup> (Schwandt, 1997 as cited in Creswell & Miller, 2000, p. 124–125). The techniques included: member-checking, peer debriefing, reflexive bracketing, and thick rich description.

In member-checking (Lincoln & Guba, 1985 as cited in Cho & Trent, 2006), participants are given a summary of the findings and asked whether the accounts were accurate and realistic, categories appropriately constructed, and whether interpretations of data corresponded with their explanations regarding the phenomena under inquiry. This occurred during the follow-up interviews (20–30 minutes), where I summarized the findings and themes and asked for feedback on whether they were accurate and represented their experiences and interpretations. This stage of the research process was beneficial for refining the pre-existing categories. As well, expanding upon certain areas allowed for more needed elaboration and clarification. All participants agreed with the findings and thought they represented their experiences accurately.

Reflexivity (Creswell, 2003) is a strategy which involves “reflecting critically on the self as researcher” (Lincoln & Guba, 2005, p. 183) and ‘bracketing’ his/her assumptions and values so as not to impose his/her own understandings on the collection and analysis of data (Ahern, 1999). This was accomplished by keeping a reflexive journal throughout the research process, self-disclosing biases, interests, and opinions. Thick rich description was also used by providing dense, deep, and detailed accounts of the social settings, interactions, participants, and

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<sup>26</sup> I acknowledge the methodological debate surrounding the philosophical assumptions associated with the term ‘validity’ in qualitative research and its positivist underpinnings in traditional quantitative research (Creswell, 2003; Trochim, 2006).

experiences. The adoption of these techniques enhanced the credibility of the study by establishing an open and honest narrative and by providing an accurate account of the findings through the perspective of the researcher, participants, and general readers (Creswell, 2003; Creswell & Miller, 2000).

I organize the findings into four chapters. In **Chapter Four**, I provide the demographics and give a detailed description of the life circumstances of the participants and their ill siblings. The intent of this chapter is to familiarize the reader with the participants and their ill brother or sister prior to describing their experiences. Chapters Five, Six, and Seven deal with distinct time periods in the participants' lives as they relate to the ill sibling's illness. Each chapter traces the well siblings' experiences as their relationship evolved with their brother's or sister's illness trajectory. **Chapter Five** describes the experiences of the well siblings growing up with their brother or sister before the onset of his/her illness and how the nature of this relationship influenced their current involvement in caregiving. **Chapter Six** reports on how well siblings' experienced their brother or sister gradually becoming ill to his/her eventual diagnosis of schizophrenia and the impact it had on their relationship. **Chapter Seven** explores how their relationships changed after the diagnosis. In particular, I describe how they related to their ill sibling, redefined their relationship, and the ways in which and forms through which well siblings' adopt the caregiving role, currently and in the future.

## Chapter 4 : Overview and Description of Participants

In this section, I describe the demographic characteristics of those in the sample and their siblings with schizophrenia.

### Well Sibling Demographics

Ten participants, five males (50%) and five females (50%), were interviewed for this study (see Table 2). Participants ranged in age from 21 to 56 years (mean=32.2 years). On average, each participant had 2.2 siblings (range=1–4 other sibling(s)). Four of the participants (40%) were older and six (60%) were younger than their sibling with schizophrenia. The average age difference between the participants and their ill sibling was 3.1 years (range=1–10 years).

All participants had some form of post-secondary education, with the exception of Claire<sup>27</sup> (10%) who had her high school diploma. Six of the participants (60%) obtained an undergraduate degree, one (10%) a graduate degree, one (10%) a doctorate, and one (10%) a university diploma. All of the participants were either employed or enrolled in a post-secondary education program. Of the three participants (30%) enrolled in a post-secondary program, one was pursuing her doctorate degree, one his Master's degree, and the last her undergraduate degree. The seven participants (70%) who were employed varied in their occupations, including a website editor, manager, trainee/teacher, marketing coordinator, nurse, radio producer, and high school teacher. The participants' occupations and educational attainment places most of them in the middle class (i.e., lower middle and upper middle class). They were all Caucasian

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<sup>27</sup> All names are pseudonyms chosen to protect the confidentiality and anonymity of the participants.

and English-speaking, with the exception of one who was of South American descent, English being her second language.

At the time of the interview, four participants (40%) were married, two (20%) were in a relationship, and four (40%) were single. Some of the participants resided exclusively with their partner or husband/wife (30%) as well as their own children (20%). Others lived in an apartment or house on their own (20%), with a roommate (20%), and with their parents (10%). None of the participants were currently living with their ill sibling, with the exception of Holden who lived with his ill sister Audrey, and his parents. However, seven of the participants had resided with their ill sibling for extended periods of time, depending on their circumstance and course of illness. Eight participants lived in relatively close proximity to their sibling with schizophrenia (i.e., in the same or a nearby city). In particular, six lived in close driving distance to their ill loved ones in order to be able to visit frequently. Although the inclusion criteria restricted the eligibility of participants to those residing in the Greater Vancouver area, three of the participants had begun to travel abroad, enrol in university out of province, and start careers afar in larger metropolitan hubs (e.g., Toronto). Despite the geographical distance between them, these participants remained in close contact with their ill brother or sister via telephone or email.

At the time of the ill sibling's diagnosis, the participants ranged in age from 8 to 29 years (mean=19.9 years). The majority of participants were in some form of schooling as most were in their late adolescence or early adulthood when their sibling was diagnosed. More specifically, four of the participants (40%) were in elementary or high school while four participants (40%) were enrolled in university. The remaining two participants (20%) were employed, one as an optical salesman and the other as a website editor. The majority of participants' parents were entering the later stages of the life cycle, with their mothers' ages ranging from 56 to 69 years

(mean=61.6 years), and fathers' ages ranging from 62 to 86 years (mean= 67.7 years).<sup>28</sup> Out of all the parents, only one mother was deceased.

### **Ill Sibling Demographics**

The 10 participants identified six brothers and two sisters as having been diagnosed with schizophrenia (see Table 3).<sup>29</sup> The ill siblings ranged in age from 26 to 46 years (mean=32.5 years), and were diagnosed at an average age of 20.5 years (range=14–27 years). They had been ill for an average of 11.9 years (range=4–31 years), although all of them were said to have been ill for a period of time before receiving a diagnosis of schizophrenia. On average, participants estimated that their brother or sister became ill (i.e., onset of schizophrenia) when they were 19 years old (range=13–27 years). The difference between the participants' estimates of the age of onset of schizophrenia and the actual diagnosis of the illness was 1.5 years.

At the time of the interview, participants reported that none of the ill siblings were involved in a relationship, nor had ever been married. In addition, none of them were employed. Joe was the only exception—he had been involved in a relationship and was enrolled in college. As reported by the participants, six of the ill siblings (60%) had obtained a high school diploma, while two of them (20%) had completed their Grade 10. Joe (10%) lived solely with his mother, while two (20%) lived with both parents. The living arrangements of the remainder were divided among group homes (20%), independent apartments (20%), and Riverview, the provincial psychiatric hospital (10%). Carter, the ill sibling of Sienna, who stays in Riverview, spends

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<sup>28</sup> This statistic has several implications for the eventual transfer of care of their ill child, the current and future involvement of well siblings, and the role of community-based services. The implications are discussed in greater detail below. The statistic also reinforces the literature that shows most parental caregivers of people with schizophrenia are entering the elderly stages of their lives.

<sup>29</sup> As Tables 2 and 3 show, I did interview three participants from the same family. Therefore, Joe was the ill sibling discussed by all three participants. As this study aimed at investigating the well siblings and not the ill ones, I count Joe as one ill sibling per participant rather than one ill sibling for all three participants when describing them in this section.

weekends visiting and staying with his parents and occasionally with Sienna and her partner.

From interviewing the participants, I found that ill siblings varied in terms of the severity of their illness, their recovery, and their illness trajectory. Overall, this sample represents a diverse group of well siblings of people with schizophrenia and, as such, represents a variety of experiences.

**Table 2: Well Sibling Demographics**

Well Sibling											
Participant	Name	Age	Gender	Current occupation/activity	Occupation/Activity when sibling was diagnosed	Education	Residence	Marital/Relationship status	Age at time of sibling diagnosis	Age of father	Age of mother
1	Troy	24	m	manager	optical salesman	university diploma	apartment by self	single	17–18	65	59
2	Ethan	37	m	nurse	student	undergraduate degree	w/partner & son	common law	18	67	65
3	Tyler	56	m	radio producer	undergraduate student	undergraduate degree	w/partner & son	married	23–26	86	D
4	Corry	31	m	teacher	undergraduate student	undergraduate degree	w/roommate	in a relationship	25–26	65	62
5	Holden	26	m	graduate student	undergraduate student	graduate degree	w/parents	single	22	65	61
6	Claire	34	f	website editor	website editor	h/s diploma	w/partner	separated/in a relationship	27–29	67	65
7	Jen	21	f	undergraduate student	student	undergraduate degree	apartment w/roommate abroad/by self	single	15	65	59
8	Amy	29	f	trainee/teacher	undergraduate student	n/a	at home/w/parents	single	25	65	59
9	Sienna	30	f	marketing coordinator	student	undergraduate degree	w/partner	common law	12	62	56
10	Mia	34	f	doctoral student	student	doctorate	w/partner	married	8	70s	late 60s

**Table 3: Ill Sibling Demographics**

Ill Sibling										
Participant	Name	Age	Gender	Current occupation/activity	Education	Residence	Marital/Relationship status	Estimated age at onset of schizophrenia	Age when diagnosed	Other well siblings by gender & age
1	Joe	26	m	college student	h/s diploma	w/mother	single/in a relationship	15–16	20	f/29, f/21
2	Chloe	40	f	n/a	h/s diploma	apartment by self	single	18	21	n/a
3	Isaac	46	m	n/a	grade 10	group home/hospital	single	13–14	15	m/54, f/52
4	Mike	27	m	n/a	h/s diploma	w/parents	single	19–20	21–22	n/a
5	Audrey	27	f	n/a	h/s diploma	w/parents	single	19–23	23	n/a
6	Luke	32	m	n/a	h/s diploma	group home	single	25–27	25–27	f/37
7	Joe	26	m	college student	h/s diploma	w/mother	single/in a relationship	20	20	m/24, f/29
8	Joe	26	m	college student	h/s diploma	w/mother	single/in a relationship	21	21	m/24, f/21
9	Carter	31	m	n/a	grade 10	hospital	single	13	14	n/a
10	Ian	44	m	n/a	h/s diploma	apartment by self	single	18	24	m/45, m/46, f/40

## Overview of Caregiving Dyads

In this section, I provide detail about the nature of the sibling relationships growing up and currently and also describe the caregiving that each participant currently provides to his/her ill sibling. The participants belong to two groups: brothers and sisters looking after ill siblings. I introduce the participants' stories and situate their experiences.

**Brothers looking after ill siblings.** *Troy*, age 24, is caregiver to his older brother *Joe*, age 26, who is the third oldest of four siblings. Growing up, Troy spent little time with Joe and described their relationship as unhealthy. Troy considered his relationship with Joe now a “good” and “strong friendship” considering “how bad it [the relationship] was at a point.” He sees their relationship as healthier than before the illness, providing Joe with more attention to make up for the past neglect. Troy enjoys going to the gym with Joe and taking “an interest” in what is “new” and “exciting” in his life. The three well siblings live separately and do not reside in the same city as their ill brother. Troy lives in Toronto for most of the year. Joe lives solely with his mother. His parents work full time, are divorced, and live in separate yet nearby residences. When he is in town, Troy stays either with his father or mother depending on the circumstances, living arrangements, and “how well Joe is” (Amy) at the time.

*Ethan*, age 37, provides support to his older sister by three years, *Chloe*. Ethan described his relationship with Chloe as “generally well” but with their share of arguments when younger. They did not do a lot of activities together except during family time. Ethan is much more involved with his sister since her diagnosis of schizophrenia and talks frequently with her regarding her issues. Because Ethan lives in a nearby city with his partner and newborn child, he believes that he provides the least amount of care to her of all those in his family. Ethan also feels that Chloe could be more independent and is therefore reluctant to be as involved in her

caregiving as his parents. Chloe has had her own apartment for the last four years. Her parents live together in the same city as Chloe. From time to time, Ethan “check[s]” on Chloe and provides her with social support. She periodically stays with Ethan when his parents are away.

**Tyler**, age 56, is the eldest of four siblings. He cares for his younger brother **Isaac**, age 46. Tyler has two other well siblings, one younger sister who is 52 and a slightly younger brother age 54. Due to the wide age gap, Tyler did not regularly interact with Isaac in their youth. Since Isaac’s diagnosis, Tyler tries to speak with and visit Isaac as much as possible. Despite his efforts to become more involved in Isaac’s care, Tyler feels he has been “shut out” by professionals such as Isaac’s psychiatrist, who is difficult to reach. He deems himself a “crisis manage[r]” rather than caregiver. Tyler lives with his partner and two adolescent children who are 16 and 19 years of age. Tyler’s mother passed away three years ago. Both of his well siblings offer little support to their ill brother. All of the family members live in the same city. Isaac has been hospitalized several times for his schizophrenia and for his addiction to crack-cocaine. During the onset of his illness, he was repeatedly hospitalized and recently had another relapse. He is being cared for at a nearby hospital. Despite his relapse, Isaac has been stable for the last seven years, living in a group home and visiting his parent(s) on a regular basis. He often stayed at their home on weekends “throughout all the ups and downs” and it was a place for him “to feel comfortable no matter where he was”. His parents were described by Tyler as Isaac’s “anchor.” Since the relapse, Tyler has become much more involved in his ill brother’s care.

**Corry**, age 30, is the caregiver to his eldest brother by three years, **Mike**. Corry lives with a roommate in an apartment near his mother’s place where Mike lives. Corry visits Mike once a week or so and believes that he is “very involved” in the care of his brother. He tries to talk with him about his goals and wellbeing whenever he can. He also encourages him to do certain things,

offers advice, and supports his mother. Corry feels that he and his brother were very close in the past and are still. Corry tries to enjoy various activities with Mike, such as playing strategy games, in an attempt to become more involved in his interests and personal life.

**Holden**, age 26, cares for his older sister by one year, **Audrey**. Growing up, Holden and Audrey spent a great deal of time together during family gatherings and trips. Once in their teens, they began to have different friends and hobbies, which led them to become more distant. In the last couple of years, Holden and Audrey have become much closer and have begun spending a lot more time together since the onset of her illness. During the onset of the illness, Audrey spent several years living on her own in a nearby city. She attended university for a brief period and eventually withdrew because of her inability to attend classes and manage the day-to-day tasks of university life. After several attempts at short-term employment, she had a psychotic episode that resulted in criminal charges. She subsequently moved back into the family home where she has been living for the last six years. Shortly after moving back, Audrey was involuntarily hospitalized and diagnosed with schizophrenia. Holden moved back in with his parents to assist them in looking after Audrey. He had previously been attending university abroad. Holden sees Audrey on a regular basis and tries to include her in his plans daily. He considers their relationship to be very close.

**Sisters looking after ill siblings.** **Claire**, age 34, is the well sibling of **Luke**, her younger brother by two years, who was diagnosed with schizophrenia at age 25. Before the onset of the illness, Claire thought they spent a lot of time together and were quite close. Claire believes that Luke has a more “comfortable rapport” with her parents since the illness. He typically calls them if he is having a crisis. Nonetheless, Claire makes an effort to visit or at least talk to him over the phone daily to see how he is doing; although lately, she has not been as good at keeping in

contact with him as she would like. She also frequently goes on walks with Luke, talks to him about her life, and helps him with his problems. She has an elder sister who lives in the USA and who is not involved in the care of her brother because of the geographical distance. Claire feels that if her sister lived locally, she would be more involved. Claire, Luke, and their parents all live in the same community. Claire lives with her partner, while Luke resides with two other individuals in a nearby group home.

*Jen*, age 21, is the youngest sister; she cares for *Joe*. Prior to the diagnosis, Jen spent very little time with Joe and considered her relationship with him as “pretty dysfunctional” and physically and emotionally “abusive.” Since the diagnosis, she has been trying to foster a stronger bond between them. Jen spends quite a bit of time with Joe when she is home and believes that they are “pretty close” now. She is a huge support to her brother, teaching him how to help their mother with chores around the house, and she acts as a role model. She attends university in a nearby city.

*Amy*, age 29, is the eldest sister of the four siblings who provides support to *Joe*. Amy thinks that their relationship growing up was “not very good” and did very little “one-on-one.” Despite the fact that Amy and Joe do not share similar interests, when she is in town she spends a great deal of time answering his questions, listening to his problems, and making sure he is on time for his appointments. Like Jen, she helps him with his daily tasks and responsibilities and assists her parents with caregiving. As the eldest, Amy feels it is her “job” to take care of Joe and expects that she will become the primary caregiver once her parents are unable to. However, because she lives abroad for her work, she believes that, of her family members, she currently provides the least amount of support to Joe. She visits for holidays during the year.

*Sienna*, age 30, is *Carter's* only and younger sister by one year. As children, Sienna and Carter did everything together. However, she did not see him much as a teenager because she moved out of her parent's house at an early age. Since Carter's diagnosis, Sienna has regular contact with him. Carter stays with Sienna periodically on the weekend. Sienna sees her relationship with Carter as "not very close," although she wishes she could do more for him. When Carter stays with her, Sienna is responsible for monitoring his medication, preparing his meals, and keeping him occupied, for example, by taking him to the mall. Now that they live in the same city, she sees him frequently and provides more of a disciplinary role to Carter. She lives with her partner and her parents live together. After repeated hospitalizations at Vancouver General Hospital and placements into various living accommodations (e.g., apartment, parent's house, group home), Carter was committed to Riverview. This was because of the severity of his illness, the lack of medication compliance, and his aggressive and violent behaviour (mainly aimed toward his father and roommates). In many instances, police became involved in order to diffuse the situations. Because of Carter's changes in residence, Sienna and her parents became involved with The Planned Lifetime Assistance Network (PLAN) to help find suitable housing for him. Sienna and her parents visit Carter in Riverview.

*Mia*, age 34, is the youngest of five siblings who supports her older brother *Ian*, age 44. Another sister is 40 years old. She has two older brothers, the first age 45 and the eldest 46 years old. Ian lives in an apartment on his own, while Mia lives with her partner. Mia thinks that, among her siblings, she has the most involvement with Ian and is a positive influence in his life. Mia enjoys taking Ian out for meals and helps Ian in any way she can financially and emotionally. The other well siblings live outside of Canada (i.e., Peru, U.S.A). Mia's parents live together in a separate residence.

## Summary

Sibling interaction and support tends to be intense during childhood and adolescence (Shortt & Gottman, 1997), lessens in adulthood (Bank & Kahn, 1982), and increases in old age (Avioli, 1989; Cicirelli, 1982, 1989; Connidis, 1989). However, as this sample demonstrates, schizophrenia can result in a different pattern of involvement in adulthood as support from well siblings' increases. The response to the symptoms of schizophrenia changed the quality of this relationship with adult well siblings and their involvement in caregiving. They became readily involved in the care of their ill siblings and support them to the best of their ability. I now turn to the nature of the sibling relationship prior to schizophrenia.

## Chapter 5 : Sibling Relationships before Schizophrenia

In this chapter, I describe well siblings' involvement with their brother or sister prior to him/her becoming sick. Specific attention is paid to the strength and nature of the sibling relationships that were evident among well and ill siblings while they were growing up in order to understand the ways in which their bond changed as the illness gradually emerged. While the siblings differentiated from one another in the teenage years, this was temporary and ultimately, their bond strengthened over time. I describe the relationship experienced by these siblings until the onset of the illness and discuss how this influenced current caregiving involvement by well siblings.

### Growing Up Together

Well siblings were asked to recall their experiences with their brother or sister at various stages of his/her life course:<sup>30</sup> childhood, early or late adolescence, and/or early adulthood. Seven of the well siblings in this study spoke about growing up in a nurturing and caring environment with positive parental role models and had fond memories of their past. However, the three other well siblings described periods in their childhood that were at times disruptive and trying for them despite generally having a positive upbringing. They depicted their families as “functional” and “healthy” social systems to be brought up in. While all well siblings stated that their families had their share of arguments and interpersonal conflicts, they agreed that their family

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<sup>30</sup> Central to the life course perspective are the several stages of development through which each individual transitions in his or her life course trajectory. These age-linked stages may include: childhood, adolescence, adulthood, middle age, and old age. The life course perspective “is guided by a number of principles concerning the intersection of social and historical factors, concepts of transitions and trajectories, and expectations of heterogeneity in life course patterns across time and place” (George, 1996 as cited in Cook et al., 1997 p. 429). It is also premised on the notion that human growth is based on the dynamics, order, and timing of social roles that people occupy at given points in the life course (MacMillan & Copher, 2005).

environments were “wholesome” and “positive,” with no major problems or issues that could be reported as “dysfunctional.” Well siblings also provided brief stories about their childhood that they genuinely enjoyed remembering. For example, Holden recalled playing with his sister in the backyard of his childhood home. During Amy’s childhood, she recalled feeling “really happy” spending quality time with her family on vacation. Likewise, Ethan reminisced about weekly “Sunday dinners” with his parents and sister and how they had a great time eating and enjoying each other’s company.

As schizophrenia typically emerges in late adolescence or early adulthood, it was expected that most, if not all, well siblings would have experienced normal sibling relationships growing up before their brother or sister became ill. Sibling relationships evolve over the life course (Bank & Kahn, 1982) and their bond usually transforms around life stage transitions (Sanders, 2004).

**Childhood.** Well siblings were asked to describe what their brother or sister with schizophrenia was like before the onset of his/her illness.<sup>31</sup> Brothers and sisters were characterized as being “nice,” “sweet,” “kind,” “bright,” “smart,” and “caring.” Other personality traits included “a great listener,” “funny,” “lively,” “highly intelligent,” “strong personality,” “witty, and a “go-getter” attitude. For example, Ethan commented that Chloe was “happy, less anxious, [and] took more initiative” before she became ill. Corry described Mike as a “contemplative person, an individual.” Mia used terms such as “calm” and “peaceful” to portray her brother Ian. These affectionate terms illustrate how well siblings regarded their sibling “very” highly. A couple of negative traits, such as “shy” and “slow” were also mentioned.

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<sup>31</sup> A couple of the well siblings had trouble remembering what their brother or sister was ‘really’ like before the illness because it was so long ago (Tyler), or that they were too young to remember (Jen). As a result, some experiences were never fully articulated.

Nonetheless, references to their brothers' and sisters' positive qualities far exceeded those to his/her negative traits during childhood.

During childhood and adolescence, well siblings primarily reminisced about how their relationship with their brother or sister was fun and intimate. The siblings carefully observed one another and learned a great deal from witnessing each other try new things. As such, siblings, like their parents, were integral to their primary socialization. It was a time of experimentation in terms of figuring out how to form a peer relationship and “negotiate, cooperate, and compete” (Minuchin, 1974 as cited in Sanders, 2004). In addition, their relationship was generally seen as reciprocal. Both well and ill siblings mutually benefitted from their relationship and helped each other when required.

Claire described her relationship with Luke: “We got along really well. It was a good camaraderie. I guess being siblings...we were quite close actually.” They communicated actively and regularly. Luke often confided in her about the problems and things that arose in his life, especially issues concerning their parents. Claire reasoned that Luke would confide in her because they both shared experiences—knowing what their parents were like and what it was like growing up in their house. Claire related to him on a deeper level than their parents, understood what he was going through, and was able to empathize with his adolescent problems and experiences. Claire stated, “I think it’s [Luke confiding in her] because I’m a sibling cause that’s always been a focus for him, family.” As a sibling and peer, she was a devoted companion and listener who he could turn to and depend on in times of need. He too did the same for her. Luke always wanted to try to help Claire with the things she was working on. Two well siblings spoke of how they spent “a lot of time” (Claire) and did “everything” (Sienna) together. Sienna and Carter were inseparable as children. She characterized them as “typical brother and sister.”

The sibling relationships were marked by interdependence and attachment as they shared a personal history and family environment.

A couple of well siblings described their relationship with their brother or sister as “generally well” (Ethan) and “good” (Corry). Ethan explained that his and Chloe’s bond was a “regular” friendship. Corry plainly called Mike his “little brother.” Tyler was “much older” than Isaac, treating him similarly like his “little kid brother.”<sup>32</sup> Tyler was predominately preoccupied with his own life, but witnessed Isaac experience childhood activities like playing with his friends or riding his bike. It can be quite common for siblings, like Tyler and Isaac, who are separated by more than eight to 10 years, to have less influence and emotional impact on one another (Bank & Kahn, 1982): “He didn’t really have much impact on me” (Tyler). As such, they participated in different activities, schools, and peers, and shared little time and space together, “I mean I was gone for a lot, like when I left, he was 9 or 10. I was 10 years older than him and I left home when he was...I wouldn’t even live at home when he was 6 or 7” (Tyler). Even so, Tyler described his connection with Isaac and his other well siblings as “pretty good.”

The close and significant bond among the siblings is consistent with past research, which finds sibling support intense during childhood and adolescence (Shortt & Gottman, 1997). A few siblings discussed having poor relationships with their other well siblings who were not around as much nor involved in their other siblings’ lives. Tyler and Claire briefly mentioned how their bonds with their other siblings differed by being less intimate because of geographical distance and their differences in age. For the most part, well siblings viewed their sibling tie as quite typical of ‘normal’ brothers and sisters at their age. Their sibling bond during these younger

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<sup>32</sup> Well siblings who described their relationship with their sibling as “typical brother and sister,” or like his “little kid brother,” left me questioning: What does it generally mean to be a “brother” or “sister”? Due to the time constraints during the interview process, it was difficult to explore this question in more depth. However, when I probed and asked what being a brother or sister meant to some siblings, they had trouble explaining it.

years would apparently serve as the foundation for their lifetime relationship. All well siblings spoke more about the warmth and affection they had for their brother or sister than about any animosity they may have felt.

Some sibling relations were also occasionally strained due to familial issues, sibling rivalry, and personality differences. Siblings intermittently “quarrelled” and “bickered.” For instance, Jen stated that she and Joe fought constantly and she “hated” her brother because he allegedly was physically abusive to her.<sup>33</sup> Holden tried to “stay away” from the disputes with Audrey as best as he could, but inevitably, he did at times argue and fight with her. Corry provided an insightful description of the antagonistic yet affectionate tie with his brother: “I was the older brother and he [Mike] was the younger brother. I would bully him and beat him up and piss him off but we were also really good friends. So I am saying that in half serious and half jest, right. We were good friends and we still are.”

Some siblings also spoke about feeling ambivalent at times toward one another: “My sister and I’s relationship always had its ups and downs as kids. Some days we would enjoy each other’s company, other days we couldn’t stand the sight of one another” (Holden). Despite his “continual fondness” and “unconditional love” for her, it was defined by Holden as a “love hate relationship.” Others expressed similar sentiments. Well siblings’ ambivalence in this study reaffirms past research on the sibling bond which maintains it is a reoccurring expression among siblings in childhood and adolescence (Bank and Kahn, 1982). These quotations from well siblings illustrate the natural ebb and flow within sibling relationships across the life course, especially characteristic of younger siblings as they mature into adulthood.

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<sup>33</sup> Jen, however, admitted she would retaliate by being emotionally abusive to Joe, teasing and calling him derogatory names. Jen also believed that the physical abuse was directly related to the onset of his condition. She stated that the physical abuse was “beyond what was considered normal.” Again, it was difficult for Jen to separate Joe’s ‘well’ self from his “ill” self at that age.

The well siblings also said that spending time together (e.g., family events, vacations) was a source of bonding that further strengthened their ties. For example, Ethan recalled having dinners on Sundays when he chatted with Chloe about “anything interesting.” Holden spoke about various family events like graduation and horse jumping contests in which they would interact. Troy, Jen, Amy, Joe, and their parents took family holidays, such as skiing and snowboarding trips. Amy elaborated: “Like family time again, family dinners or watching movies together... not forced activities but activities that we would all do together because it was a family thing.”

Growing up together, eight of the 10 siblings spent a fair amount of time together and shared much with each other. For example, Corry would watch movies, play chess, computer and strategy games, such as Dungeons & Dragons, and “shoot hoops” with Mike. Sienna and Carter also entertained themselves with video games. Alternatively, Claire and Luke would do “normal day-to-day stuff” like going out for lunch, sometimes daily, and frequented parties together. Holden recounted similar activities, such as partying and experimenting with recreational drugs with Audrey. Ethan and Chloe played music together and enjoyed card games. Chloe tutored him with his homework as well. Siblings indulged in childhood and adolescent high jinks.

All siblings were also described as having close friends with whom they interacted regularly. The number of friends ranged in size from “one or two” to a “group,” with most having “few” friends. Some siblings socialized and played with the same friends and peer groups. Frequent daily contact living in the same household and being enrolled in the same or a nearby school was also reported by well siblings as a form of increasing involvement with their brother or sister. For example, Jen rode the school bus home with Joe every day from school. Generally, the brother’s or sister’s schooling at the beginning was of “no real” concern for the

parents and well siblings. The ill siblings “got by” like any of the other students in their class. Their grades ranged from satisfactory to excellent.

Several well siblings recalled their brother or sister as having hobbies and being involved in sports. Joe played soccer, rugby, lifted weights, and took martial arts classes. He enjoyed math and sang, sketched, wrote, and read. Audrey loved to draw, specifically paint, played guitar, and partook in rhythmic gymnastics and ballet. Ian was an artist who also read and played chess. He frequently exercised along with a couple of his siblings and was a rower. As a “very active family” (Troy), Joe’s father, Troy, and Jen all played soccer, allowing the family to spend valuable time together. Similarly, Carter was an avid football and rugby player whose parents took him to football camp seasonally to practice. He also played video games and did “typical teenage stuff” (Sienna). Isaac joined the school band, played the saxophone, and was also involved in the Navel Cadets. However, as Isaac entered high school he started to define himself as one of the “top notch stoner[s]” as opposed to being one of the “cool people,” “jocks” [and/or] “real geeky guys.” He smoked a lot of marijuana and did acid repeatedly. These became his main pastimes. In contrast, Corry’s ill brother Mike was not athletic nor involved in drug activity, and was on the dean’s list in college, receiving “straight A’s in everything he took” (Corry). He excelled in educational pursuits and was passionate about many subjects, such as philosophy, history, and debating. Ill siblings were portrayed as capable individuals who were able to balance a number of things. Ethan recalled the following about his sister Chloe:

Something that came up on her 40<sup>th</sup> birthday was that my dad was giving a speech and went into details regarding what she was like before the onset and that she was very musically gifted. She won a scholarship to go to university for music, she was outgoing with her friends, had a spark to her, really likes doing things in the outdoors like hiking or going to the Rockies, that sort of stuff.

These comments illustrate how the well siblings perceived their brother or sister as having great potential in their youth.

It was accepted by well siblings that their brother or sister would go on to lead a productive life and remain close. However, most well siblings gradually began to distance themselves from their sibling during adolescence.

**Adolescence.** Growing apart in adolescence was a common experience for the majority of well siblings.<sup>34</sup> Adolescence marked a transition when they began to form a social identity outside their family and when they began to care much more about how they presented themselves and how others perceived them. All well siblings mentioned having a desire to be independent from their families and adopting new social roles with added responsibility like that of a “student” or “peer.” Accordingly, well siblings paid less attention to their brother or sister and sibling bonds weakened. As Ethan commented, “I think I noted that I was 18 and she was 21. So we were sort of independent already...in terms of the age thing, we were doing other things...I think I was off in my own little world at around 18 or 19.” At those ages, Ethan and Chloe engaged in things that did not directly involve one another. Sienna similarly pointed out, “We were close up until I become a bratty teenager...I kind of separated from him at that time. So we definitely diverged at that point.” Simply removing themselves from their brother or sister and family seemed the easiest and most plausible way to attain their own independence. Ethan’s withdrawing into his “own little world” can be quite natural at this stage of a teenager’s development; a time of self-reflection and contemplation. Indeed, it is a basic cultural assumption that teenagers are “neither here nor there” but in a liminal period (Aubrun & Grady,

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<sup>34</sup> It is important to note that, as the age of well and ill siblings ranged among them, some were still in different stages of their development. This was also the case for when their brother or sister became sick and was diagnosed. For example, Jen was still in elementary or middle school when Amy left for university. Despite this time line, all well siblings proceeded to gain their independence and gradually grow apart from their sibling as they matured into adulthood.

2000). These formative years were influential in developing their sense of self and acquiring social roles and identities that they internalized. The teenage years were when well siblings sought to “branch out” from their family environment. More specifically, their social networks expanded through meeting love interests, new friends, and peers, from school, work, or social settings. Well siblings immersed themselves in these social environments and networks that their brother or sister were largely not part of. Yet, the unique social and scholastic settings siblings visited may or may not have been dissimilar.

Well and ill siblings advanced through their education, often in separate directions. Holden defined his sibling bond with Audrey in his late adolescence, “by the simple fact that we had our own lives. She went to her high school, I went to my high school.” Holden and Audrey transferred schools a number of times growing up because of their father’s career, which forced their family to move periodically. On many occasions, sibling school experiences were quite dissimilar because of the types of schools they attended. For example, Holden attended a boarding school and all boys’ Catholic school, while Audrey went to both public and private schools. Sienna similarly noted:

We went to different schools. I was in French immersion and Carter was in English school. I had to catch a bus and he walked to his school. We were doing our own thing like I was in gymnastics and he was doing football and going swimming and playing video games. So those things were quite separate, but as kids we did everything together.

With eight of the siblings attending different schools, the amount of time they spent together decreased. Even when some well and ill siblings attended the same school, distancing still took place:

We were at that age where we would go out and try to do our own thing and I think some of it is that I think, growing up, my sister was teased and I didn’t want myself to be teased. I remember coming home from school where she was teased and they were trying to tease me too and I just walked away. So I think that this sort of distancing started in terms of when we were out and about (Ethan).

Ethan attempted to “stay clear” of Chloe to avoid being teased like she was. Joe was also picked on in high school. Troy spent very little time with him and recalled that he “didn’t stick up for him really or anything. I mean if someone really crossed the line then yes, but not really, no.”

Well siblings gradually became more dependent on their peers, and less dependent on their sibling(s). Friends increasingly took a more substantial place in well siblings’ lives. Holden concisely stated, “She had her friends, I had my friends. I thought they [her friends] were kind of strange and weird; because of that I did not interact with her or them.” Some of the siblings changed their looks, dress, friends, and so forth in search for their “true” sense of self. Audrey underwent numerous transformations in her appearance and made many new and eclectic friends that differed from her past ones. Holden could not relate to them or to her, thereby making it hard for him to remain close to his sister. He too altered his appearance and friends in order to find his distinct identity.

Sienna mentioned, “I was just more concerned with my friends and with anything that hadn’t to do with him.” Her mother always attempted to “make” her friends become Carter’s because he had so few of them. Her mother even went so far as to have her 25-year-old younger brother emigrate from Honduras to Canada. He became Carter’s friend and they spent a lot of time and did many things together. She went on to state, “especially at that age, like if I was older maybe it would have been different, but at that age—forget about it you know, plus he wasn’t there [in a nearby city], he was in Vancouver.” Sienna implicitly acknowledged how, at that age and time in her life, it would have been “forced,” inappropriate, and disruptive to try to persuade her friends to include Carter into her tight-knit social group. Corry gave a comparable account: “So for most of the teens, there’s still that big age gap. If I’m 18 and he’s 14 there’s still a big difference, right?... He wasn’t coming to meet my friends because I was a lot older than

him.” Corry realized the intricacies of having a younger brother who wants to “tag along” and be involved in his affairs and social circles, which seem so appealing and “cool.” Corry justified that Mike was not old enough to hang out with his friends. When I asked Sienna whether Carter not having friends made her feel a certain way, she replied, “Yes, I mean I guess I felt bad for him for sure, but it was high school; high school was hard enough for me, so to have to think about him.” Similar to Ethan’s experience of avoiding his sister because he did not want to be teased, Sienna alluded to the difficulty of being a teenager in high school. In order to manage the best she could, she primarily focused on her own needs and issues and neglected Carter’s.

For Troy, friends became much more prominent than family in his life. Troy went so far as to say that his friends actually became his family for a period of time: “I would say, in my situation, my friends were my family for the majority of what I remember.” He began to spend more time with his friends’ families and “adopted” them because he preferred their nurturing environment to his own family situation. He would periodically stay over at their houses for three to five nights a week. He remembered it being not a healthy and “positive place really.”

As well and ill siblings matured, personality and age differences (i.e., sibling order and closeness in age) became more influential. For example, among Joe’s siblings, Amy elaborated that she did not “even do things” with Jen “one on one” because she was eight years younger. Jen was portrayed as “always the baby” (Amy). Siblings, who are eight to 10 years apart, like Amy and Tyler are to their youngest siblings, seem almost from a different generation. Amy and Tyler thus did not have “a lot in common” with Jen and Isaac. The younger siblings may have felt alienated and left out due to their age and maturity level. Alternatively, they may have viewed their eldest brother’s or sister’s world as foreign and intimidating as well. In contrast, Amy, who was five years older than Troy, hung out with him regularly. They got along better

than their other siblings. Joe, who was only three years younger than Amy, presumably should have had a stronger relationship with Amy than Troy. Her case illustrates how their closeness in age allowed the siblings to remain closer to each other.

**Early adulthood.** As time passed, well siblings began embarking on their own unique pursuits, aspirations, and goals in order to fully become self-reliant and financially self-sufficient. They engaged in social roles and experiences that would be fulfilling, challenging, and purposeful. Many had to leave their home, local community, city, or even country, to accomplish this. Several siblings began to attend post-secondary education either full- or part-time, while others travelled afar. For example, Holden enrolled in a nearby community college for a year, then transferred to a university across the country to attain his bachelor's degree. Corry and Amy also began attending university once out of high school. Ethan, on the other hand, decided to work full-time at a restaurant after high school and before pursuing his secondary education. Tyler attended university and decided to travel for three years in his early twenties, when his brother was much younger. When I asked him more in-depth about his relationship, he responded: "I mean, I just wanted to get out of there and live my life. It was like [the] 60s early 70s. I wanted to get moving and I wanted to see the world. So what was happening at home was such a minor interest to me" (Tyler). He also spoke of how, when he was away, some of his friends got Isaac "stoned," which he found out years later. It was upsetting and disappointing for Tyler that his friends would use peer pressure on his younger brother to make him experiment with drugs. In Sienna's case, once Carter was hospitalized and subsequently transferred to a psychiatric hospital in Vancouver, their parents decided to come and stay with him so that he would be better looked after. Under the circumstances, Sienna was left alone in their house in a rural town in Interior British Columbia for extended periods of time. This resulted in many

problems between Sienna and her parents because “I kind of had the freedom to do whatever I want and they would come back and impose these rules on me and I was like, “forget it, right!” At age 15, she moved out of her parent’s house, attended school, worked and “kind of realized myself from that point on.”

The relationship of well siblings with their brother or sister became less central in their lives as these other things gained more importance. These findings reaffirm research on the sibling bond through the life course perspective that predicts a decline in the sibling relationship in early adulthood (White, 2001).

## **Summary**

Growing up together, well and ill siblings had an intimate and affectionate relationship during childhood and early adolescence, spending a great deal of time together despite some periods of instability. However, as siblings matured into the later teenage years, they socialized less with their family and more with other individuals with whom they connected through their hobbies, interests, and so forth. This process was influenced by an array of factors, including parental pressures and expectations, geographic mobility, employment opportunities, and university education. A few well siblings reported that their other siblings did not have as close a bond to their ill brother or sister as they did. This influenced the amount of support their other siblings provided, which was minimal, once he/she became ill. As well siblings were gaining their independence, their brother or sister began experiencing the early symptoms of what would be diagnosed as schizophrenia. The next chapter describes this period in the lives of the well siblings.

## Chapter 6 : The Diagnosis

In this chapter, I describe what happened to the ill sibling during the onset and diagnosis of schizophrenia and how well siblings felt during this period. More specifically, I provide insight into how they struggled to understand the drastic changes in their sibling's development, mainly toward his/her behaviour, relationships, and lifestyle choices. I also address how the well and ill siblings' relationship was impacted across three phases of the illness: (1) the prodromal phase,<sup>35</sup> (2) the active phase of symptoms, and (3) the residual phase following the psychosis.

### Suspecting Something was Off

From the prodromal phase until the time of their sibling's diagnosis of schizophrenia, most well siblings were embracing their independence and were immersed in other things, such as schooling and work, as the majority were in adolescence and early adulthood. Six well siblings had moved out of their family homes and into their own apartments, houses with a partner, roommate(s), or alone. For instance, Tyler explained:

I was involved and then I was kind of not involved because I was not living at home, going to university, and I was breaking up with this girl and there was all these things going on in my life. Going tree planting and going off for months at a time and working but during all this sort of time they [his parents] did get him diagnosed. He was in and out of hospital and things got way worse before they got better.

Tyler's pursuits influenced his level of involvement when Isaac's mental health progressively deteriorated. He said, "To be honest I was totally focused on my own life and didn't even have much of a relationship with Isaac at that time [when the illness was emerging]." Similarly, when Chloe began to experience difficulties in her work, Ethan recalled "I probably just didn't pay that

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<sup>35</sup> The prodromal phase of schizophrenia refers to "the time from the first noticeable symptoms to the first prominent psychotic symptoms" Beiser et al., 1993 as cited in Yung & McGorry, 1996, p. 353). This phase may last weeks or even years before the psychosis emerges.

much attention.” In Sienna’s case, she stated: “At that age, I just sort of distanced myself from him, I didn’t know how to take it. So I lived my life apart from him and I really didn’t want to have him a part of my life and I wasn’t involved in his life at all.”

Eight of the well siblings were seldom around their brother or sister. As a result, they did not encounter first-hand the early indicators of the illness, such as the deterioration of functioning: “I think from what I heard [from my parents]...cause I wasn’t around I was at university from 18 and that’s kind of really [when it] started and Joe was around 14 and that was when it got progressively worse. The whole time things were really bad at home. I wasn’t here to experience it at all” (Amy). Others expressed similar remarks. When Holden came home from university to visit during holidays, his parents cautioned him that “Audrey is being very temperamental.” Holden deduced that his parent’s warnings about Audrey’s behaviour implicitly meant his sister was not “in the right mind space” or in “one of her moods,” despite being confused as to what caused her outbursts and irritability. The lack of social contact with their sibling often made it challenging for some to directly notice, and become aware of, the escalating changes in comparison to the extent their parents and others were witnessing day to day. Nonetheless, well siblings, at some point, began to speculate that their brother or sister was experiencing increasing personal and social problems as he or she matured. They suspected “something” was “off” and attempted to understand their ill sibling.

Suspecting something was off was marked by events and behaviours the families experienced early in the course of the illness. Early psychotic signs and symptoms had occurred either gradually or rapidly, but in all cases, culminated in an acute psychotic break.

Parents were the ones who primarily noticed the initial changes to their child. They became concerned and apprehensive for their child’s well-being, relaying this news to their other

well children. In a few cases, close friends of the family became concerned and felt the need to express their sentiments to the sibling's relatives. For instance, when Tyler and Isaac's parents went on a dream holiday to England for six weeks, a female friend stayed at their house with Isaac. This woman's mother had suffered from a SMI and had committed suicide years ago which made her cognizant of the early signs and symptoms of mental illness. She said to Tyler: "Either your brother is really trying to freak me out or there's something wrong with him and he has some kind of mental illness or something[s] happening." Once Tyler was given this alarming information, he discussed his brother's behaviour with others in hopes of getting a better understanding of the underlying issues. At the time, Tyler was living with a woman whose sister was studying psychology and was highly educated on the subject. She thought he had schizophrenia and had Isaac meet one of her professors who felt that "a lot of these things were pointing toward schizophrenia."

Eight well siblings reported receiving phone calls on a regular basis from parents in a panic and clueless as to what was happening to their child. For example, Troy received numerous phone calls from his mother regarding Joe's early psychotic behaviours, such as lodging a vacuum cleaner up the chimney and putting mattresses up against the windows. Parents' urgency to call their well siblings arose as a result of numerous dramatic and negative alterations to their child's personality, behaviour, and lifestyle. Most well siblings already suspected that "something" was "off," "wrong" or "just not right" as indicated by the following comment by Troy: "Ok. The time when I really knew there was a problem... I was either 17 or 18 and it just became really clear overnight that something was wrong." All well siblings repeatedly used the terms "off" and "wrong" to describe their initial reactions to their brother or sister. Interestingly, well siblings often used the term "something" to explain what was happening to their sibling.

The use of this term suggests that the well siblings lacked an understanding of what was actually occurring. For example, Jen said she had an inkling Joe was “going a bit crazy” but did not know it was schizophrenia at the time.

In the next section, I describe the early symptoms of schizophrenia from the family’s perspective in more detail. I have organized these symptoms into three categories: (1) abnormal behaviour and personality changes, (2) work and school issues, and (3) psychotic signs.

**Abnormal behaviour and personality changes.** Well siblings spoke of how their sibling began to act in unsettling ways and to behave abnormally. They described the ill sibling in terms of “not being very social,” “weird,” “irritable,” “difficult,” “different,” “slower at most things,” “violent,” “verbally abusive,” “aggressive,” “mad,” “bad temper[ed],” “intense,” and “demanding.” For example, Claire mentioned that Luke was “quite argumentative” immediately before the onset of his illness. Three well siblings (Claire, Troy, and Jen) described their respective brothers as “socially awkward.” For all well siblings, their sibling’s negative temperament caused occasional disruption in the family. Holden recalled how Audrey’s behaviour was tumultuous and unstable:

I was kind of scared of her a little bit. She was always aggressive. I really didn’t like the fighting. I’m more of a subdued, calm person so I didn’t like to have conflict and when she always did get angry, she always had to have some kind of issue going on. When that happened, I always wanted to get away from that kind of environment. I think that speaks to our relationship too.

This type of abnormal behaviour made it difficult for well siblings to maintain a positive and affectionate relationship with their brother or sister. Arguments would arise when well siblings confronted their brother or sister to find out what was wrong. Well siblings reported being treated harshly, rejected, and put down—even threatened—by their ill sibling. They were “fed up” and tired of the treatment their loved one put them and their parents through and were

puzzled as to how someone so close to them could change so drastically and act this peculiarly and strangely. Even so, they still had a strong desire to help their ill sibling but felt unsure, cautious, and powerless over what to do. They became more desperate to figure out how to manage their sibling's behaviour more effectively. They also attempted to handle the fluctuations of the illness by monitoring symptoms that were becoming more severe.

The ill sibling began to regress in social skills. This type of behaviour was embarrassing, confusing, and intensely stressful for well siblings. This was most obvious during family and social gatherings, especially at dinners. For instance, Mia's brother Ian withdrew from family dinners, which he previously enjoyed and where he would socialize with other relatives. Like Ian, Chloe, Ethan's ill sibling, would have "crying spells" during family occasions and when guests were over. She frequently had to "excuse herself" from the situation in order to deal with her uncontrollable emotions to try to calm and compose herself the best she could. Following a similar pattern of behaviour, Holden described how they had to "walk on eggshells" around Audrey to make sure she did not "snap" or "just randomly yell at someone or freak out if they touched her or even gazed at her in passing." Audrey's paranoia about her father and close family friends touching her inappropriately became a regular occurrence. When they would have contact with Audrey, she would often scream and curse. Eventually, her parents stopped inviting people over to their house. Four well siblings recalled how their siblings caused a disturbance in public. For example, Holden remembered that during one family vacation when they were out at an expensive restaurant in Florida, Audrey tossed a bread roll at her father. Holden was enraged at his sister's behaviour and ran to the washroom to cry so his parents would not see the pain it caused him.

When ill siblings behaved inappropriately around others, the family engaged in what Goffman (1963) calls “stigma management” in order to “cover” their loved one’s discreditable behaviour that could arouse suspicions that their affected relative was unhealthy. This was accomplished by “restrict[ing] the display of those failings most centrally identified with the stigma” (ibid., p. 103). In trying to conceal their loved one’s abnormal behaviour from others, well siblings often employed techniques of information control. They lied to others and try to hide the fact that their brother’s or sister’s mental health was progressively deteriorating. They only shared this sensitive information with close friends and relatives.

Other problematic behaviours identified by well siblings included unusual sleeping habits and routines that isolated them from the rest of the family. Many ill siblings withdrew socially to their bedrooms and would “stay up later” even at “all hours of the night” (Holden), while others were “really high” and “sleep all the time... [and] all day and watch TV all night” (Sienna). For example, Mike was awake all night on his computer and reclusive, Audrey wrote on the walls of her bedroom, and Carter watched his TV at extremely high volumes in his bedroom and would “laugh at nothing.” Other family members found these behaviours so troubling that they became selective as to whom they allowed into the house for fear of a “scene” or embarrassment. They almost became “prisoners” in their own home and were very careful in how they interacted with the ill sibling for fear of exacerbating his or her symptoms.

Changes in personality were another early sign of schizophrenia. Three well siblings described their brother or sister as being “moody.” As illustrated in the quote that follows, well siblings questioned what was happening to their brother or sister, whom they thought they knew so well from growing up together: “I thought what she [the mother] told me was completely out of character for Joe, very strange” (Amy). Claire talked of Luke getting into “power struggles”

with his teachers in high school and college. Luke began to have a serious problem with authority and believed that they were either putting “him down” or “in his place.” As a result, he would lash out at them and get in heated arguments on a regular basis. Well siblings strove to understand these unexplainable changes in their sibling’s personality and tried to control his/her symptoms accordingly. Others described their sibling as becoming emotional, fearful, depressed, euphoric, absent-minded, and nonsensical. The bizarre behaviour and changes in personality also negatively impacted siblings’ relationships with, not only their family, but also peers, friends, and co-workers.

Seven well siblings reported incidents of violence involving their sibling. Three of them divulged that the authorities became involved and the ill sibling was subsequently charged by the victims. For example, Carter, Sienna’s ill brother, has had a couple of episodes of violence involving their father who he would physically hit. Sienna explained: “I’m his sister, so sisters and brothers fight, right? But when it comes to my dad, I can’t see it. If I’m around it I get so angry I would blow up at him and then he (Carter) gets angry at me.” This quote reveals that Sienna distinguishes between her sibling role to her father’s parental role. Each role has a set of expectations and behaviours that are believed to be appropriate or inappropriate. In this case for Sienna, fighting, even physically at times, is considered appropriate for siblings while being excluded from acceptable parental-sibling interaction. She also spoke of how her dad “takes it” and “feels bad,” while Sienna is the one who usually calls the police. In addition, Carter caused property damage, such as breaking windows and smashing TVs.<sup>36</sup> While his parents tolerated

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<sup>36</sup> Carter continued to have violent outbursts and numerous altercations with police and others. Because of this, he was transferred repeatedly back and forth from a psychiatry unit in hospital then discharged to go live back with his parents or in an apartment. During this period, they connected with PLAN and they and the family agreed that “he [was] too aggressive” to remain in the community. Thus, he was committed to Riverview Psychiatric Hospital, where he now resides.

Carter's violent outbursts, Sienna was less tolerant: "I think he needs to know that it is wrong...like he knows right from wrong; he was raised the same as I was. He does know what is wrong and what is right...I just think there needs to be some form of punishment for what he does." Carter also killed one of the family's pets, which horrified Sienna and still causes her great pain. Holden spoke similarly about Audrey's abusive behaviour. For example, she had an altercation with him and hit him over the head with a beer bottle. She was charged with abuse. Claire's ill brother Luke attacked one of his roommates and was charged with assault.

The well siblings were also targeted for physical abuse. For example, Tyler recalled that Isaac had "gotten physical" only once when he attempted to strangle his mother a few years ago. Jen felt that Joe physically abused her numerous times in the past and resented her parents for not stopping it sooner. She discussed how her mother blamed the abuse on the illness. However, she felt that this was not a reasonable justification for his behaviour:

I have talked to my parents about it and about the physical abuse stuff and my mom has distanced it quite a bit on 'oh Joe was just sick.' She kind of has acknowledged it more that it was wrong now but he can be sick and not be physically abusive. I think there's a difference...He was really angry and had probably really felt a loss of control from feeling whatever he was due to the schizophrenia but there are different ways to display anger and I think there's a reason why he hit me instead of, say, my brother or my sister or my mom.

Troy confirmed that Jen was abused by Joe but specified, "Now it does not appear to be a sexual abuse, it appears to be more of just being intimidated and not feeling safe around him." While interviewing Troy, his father entered the room and added to our conversation, "I think she actually blames her mother and me to a greater extent for not offering better protection against Joe. There's a sort of feeling that it's really more our fault than it is actually Joe's fault." The violent episodes were traumatic for the well siblings and they still had difficulty forgetting this dark period of their relationship with the ill sibling.

**Work and school issues.** Ill siblings in their adolescence and early adulthood began to experience occupational and academic problems. With the symptoms worsening and becoming more apparent, ill siblings' performance at school or work began to steadily decline. Well siblings described their sibling as becoming "irresponsible" and "careless." Those siblings who were employed were unable to hold down their jobs for long periods of time because they could not sustain the level of performance needed for the job, felt irritable and overwhelmed, and/or lost motivation or did not want to continue working there for various reasons. For example, Ethan recalled one summer when Chloe worked as a house cleaner and how she found the job too demanding. Other well siblings gave similar stories regarding their sibling's occupational dysfunction.

Several had difficulty maintaining their grades. Six ill siblings were unable to complete their post-secondary education. For example, Mike had failed most of his classes and "quit" because he did not care anymore, despite a previous fondness for learning and an interest in philosophy. Similarly, Chloe, Audrey, and Ian had to "pull out" of university after a time due to failing grades. Claire said that Luke attended a technical college and had a job nearby but because of perceived conflicts with students and co-workers, he was unable to complete his education and left his job.

As Bota and associates (2008) confirm, "patients who will develop schizophrenia have certain difficulties in multiple developmental and achievement areas, long before the prodromal period" (p. 219). This was the case with four well siblings who believed the early symptoms of schizophrenia contributed to their sibling's troubles in school. For example, Claire correlated Luke's withdrawal from school activities to the emergence of the illness. Amy, at age 13 or 14, asked her parents repeatedly to get Joe tested to see if he had any learning disabilities. Troy

sympathized with Joe's difficulties in school: "You know, it made me do a lot of thinking about how he was treated in high school and elementary school and it's just too bad that such a nice guy had such a shitty time growing up because something was missed or something was off." Likewise, Sienna said that her brother Carter began having troubles in school, fighting with students and not doing his homework. At age 13, he began "missing school" and "he would hang around where we lived and people would see him around and you know that's when they had to hospitalize him when everyone finds out." Although these problems were caused by the early symptoms of illness, most well siblings at the time believed that their ill siblings were merely being irresponsible and neglecting school or their work.

**Psychotic symptoms.** Psychotic symptoms were the most distressing indicators for well siblings that their brother's or sister's condition was worsening. Positive symptoms such as hallucinations are typically more obvious than the negative ones because "they occur on a continuum of normality, are non-specific, and may be due to a variety of other factors" (APA, 1994, p. 277). Well siblings gave an account of one or more psychotic episodes(s), including auditory or visual hallucinations, thought disorder, or delusional thinking.<sup>37</sup> For instance, Amy recalled how her brother Joe felt that a "Vietnamese gang [or ninjas] were going to come and kill him" (Jen). Joe panicked and reacted by "stuffing pillows up the fireplace and locking all the doors and nailing stuff like clothes [to the wall]" to prevent them from coming in. Jen was the only well sibling who witnessed this episode with her mother. Troy added: "he lodged the vacuum up in the chimney and he was like literally that scared that he put a mattress against the

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<sup>37</sup> APA defines delusions as "erroneous beliefs that usually involve a misinterpretation of perceptions or experiences. Their content may include a variety of themes (e.g., persecutory, referential, somatic, religious, or grandiose)" (APA, 1994, p. 275). Auditory hallucinations are "usually experienced as voices, whether familiar or unfamiliar, that are perceived as distinct from the person's own thoughts" (ibid). Thought disorder is when the speech of individuals is disorganized in a variety of ways, such as speaking incoherently.

window or whatever, literally that scared that he felt like he had to do stuff like that.” During another episode, Joe told his father that he killed his brother Troy. Troy said that, at the time, his “parents were trying to get a hold of him” and “apparently they were looking for him in the bushes or something” because he went to his girlfriend’s place and did not inform his parents. Tyler recounted a time when Isaac believed that “people [were] coming into his room at night and taking spinal fluid from his back” and “tapping him.” One night when Holden and his sister were talking alone, Audrey confided that she thought there were “Nazi concentration camp trains and that people were being put into them by her father” and “Central Intelligence Agency (CIA) paraphernalia installed in the family car and the house was bugged and that her dad sexually abused and molested her.” Families were often a part of the delusional system<sup>38</sup> of people with schizophrenia. Like Audrey, Corry’s brother Mike had certain delusions that were persecutory. One time Mike insisted that Corry not use the phones in their house because their “lives were in danger” and “that they’ll [the government] know and they’ll find out and get them” (Corry).

Corry described one such episode:

We drove off to Fort Langley from North Vancouver cause Mike wanted to show us an experiment, but he wouldn’t tell us where we were going. We didn’t know why. All that we knew is that he wanted to show us something. So we were doing this and I remember sitting in the car with my dad, my brother, and we’re all dead quiet, we’re not talking to each other and I am just thinking like, can I be [on] candid [camera]? Just like, fuck what is going on here! I remember saying “ok where are we going Mike?” and Mike said “just drive, I can’t say” because he was afraid that someone was following us or [that] people discovering that he knew but of course he was not telling us this. So we get up to Fort Langley to some park and he sets up objects in this path that we are supposed to walk. It was about 500 metres or something and we’re supposed to walk around the certain things and you know my dad does it and Mike asks him questions. Of course it’s not what Mike expected because Mike’s thinking something about like things only exist if you think they exist or something like that. It was actually some theory that people had done 50 years ago and it ended and no one pays attention to it now right, other than people

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<sup>38</sup> Auditory hallucinations and delusions are among the most prominent and common signs and symptoms of schizophrenia. More than three quarters of all individuals suffering from the illness will have one or the other (Torrey, 2001, p. 179).

studying first year philosophy. So my dad and my brother get into this big argument and I don't think my dad should have been upset and I didn't know why my brother was proposing these things to my dad which don't make sense at all and everyone's upset and I'm thinking ok. So we're driving back to North Van and so it was that day. We were all concerned and we knew something was wrong but we didn't know what.

When I asked Claire about her experience with the initial symptoms of the illness, she touched upon Luke's delusional thoughts regarding their parents but found it difficult to decipher if they were true or false accusations: "when I look back on it, some of it was delusional but there was always such a grain of truth of what my parents were like and what growing up in our house was like. So it didn't quite occur to me maybe that he was having even more delusional thoughts than that."

Siblings experiencing these episodes were in complete shock and devastated that their brother or sister could have such ludicrous ideas. They tried to understand their sibling's behaviour at the time but were unable to because of a lack of knowledge and because the ill sibling had not been diagnosed yet. Instead, they speculated about the cause of these dramatic changes and were starting to guess that perhaps it was time to seek professional help.

### **The Guessing Game**

The period preceding the diagnosis was like a guessing game. Family members knew something was "off" but first rationalized the disturbing behaviours. For example, Corry and his family felt that Mike was battling depression and did not realize that it was psychosis until he was diagnosed. Amy speculated that Joe had "gotten into drugs" because he was around the age of 18 or 19 when teenagers usually experiment with these types of things: "who knows like maybe he's having a bad acid trip... [He] could have partied too much. [We] had to get him into rehab is what I thought." Troy also thought Joe was experimenting with mind-altering substances, specifically alcohol. He and his family members would often find liquor bottles in

Joe's room. Tyler partly attributed Isaac's experimenting with drugs to the onset of his illness. In contrast, Sienna and her family believed Carter was experiencing a nervous breakdown when he was having his first psychotic break.

A few well siblings normalized their sibling's personality and behavioural changes. Holden reasoned that Audrey's outbursts were typical for a female teenager to "act up" and have "temper tantrums." Ethan rationalized Chloe's inability to complete the simple tasks required of her house cleaning job and subsequent dismissal could have happened to anyone and might not have been due to the illness. Tyler, when confronted by his friend with concerns regarding Isaac's mental health, thought his abnormal beliefs were routine for him: "Well, then I talked to him and I was thinking, well, it's cause he always had these weird ideas about the world and was asking all these questions about the universe and I was thinking this is maybe normal." Clueless as to what was happening to their siblings; they reasoned that these changes might be typical of individuals at their stage of the life course. Given the gradual decline of the sibling's mental health, it was difficult for family members to separate adolescent experimentation and "growing pains" common among youth, from an underlying mental health problem. Their lack of knowledge regarding mental illness exacerbated this issue and was a barrier to their not realizing sooner that their sibling was not just rebelling, but actually sick.

Some parents were in denial as well. They refused to believe that their child was sick or had a "hard time accepting the fact" (Sienna) that their child suffered from schizophrenia. These parents also justified it as normal teenage behaviour. Tyler began to talk to his parents about his concerns:

Now, my parents were obviously not quite eager to embrace this idea but, given my own family history, they knew that they [had] some experience with mental illness. My dad is a doctor, for one thing, and so he is a scientifically orientated guy and his own mother was very seriously ill. He had his own breakdown. It wasn't as if there was no

experience. There was some denial but then we did convince them that it was not normal and that he could pull it together and speak fine but when you talked a little longer and got a little deeper, you'd realize there were these things going on that he was really troubled by (Tyler).

Jen and Amy also tried to influence their parent(s) recognition of the severity of the problem.

They found them to be in denial of the warning signs:

Well my mom was trying to convince my dad that something needed to be done because I think my dad was in denial about it for quite a while. But I remember my mom just kind of being really frantic about wanting him to get help and that, because my dad's a doctor, he has kind of the resources. [He] knows obviously what he can do about it. So I remember it being a struggle for my mom to get my dad to admit that there was something wrong with Joe (Jen).

The schizophrenia option was on the table for a couple of years, and it was not concluded upon for quite a long time, and my mom blames my dad a lot for that because he held back some pretty important information about his family. Like his mom, of course, we all know is psychotic, but his grandfather was in an institution his whole life with schizophrenia. So he didn't disclose this information initially, which probably would have been helpful. So my mom was a little upset when the final diagnosis was concluded. You know like "hello" you could have told us this a couple years ago (Amy).

Interestingly, in these two cases, there were family histories of mental illness and the well siblings' fathers were aware of the symptoms of schizophrenia because of their medical profession as doctors. However, they were still reluctant to admit there was a problem. Faced with a child whose behaviour was becoming more problematic, parents had a difficult time coming to terms with their child's illness and postponed dealing with it until it became too much to bear. When I asked Jen how the parental denial and friction affected her relationship with them, she answered: "I knew that it was a big strain on it because I remember my mom pushing so hard for something to be done and my dad just saying that there was nothing wrong and he's normal and all that kind of stuff." I further asked how it made her feel: "I don't know. I guess I kind of relate more to my mom, 'if you know something's wrong then something should be done' and frustrated that my dad had all this access to resources and just wasn't using them."

Well siblings in these cases often had to persuade one or both of their parents that something was wrong with their sibling and to seek professional help.

In these cases, well siblings acted as mediators between their parents and the ill sibling to ease the tension and resolve the disputes. They also were “caught in the middle” and had “divided loyalties” between their parents and the ill sibling. Well siblings were in a unique position in the family, relating to both the parents and the ill sibling’s perspective and desires. For example, when Mike and his father got into an argument regarding his delusions, Corry was forced to mediate:

He [Mike] was talking to dad about something and he was getting really frustrated and ‘it doesn’t make sense Mike just Rrrrr!’ realizing that he is sick. So we’re all puzzled and kind of scared. My dad was pissed off and my mom was not at the house. I was caught in the middle between my brother not making sense and being really confused of that and not wanting my dad to be angry at him because I could see that Mike was really unhappy.

Eventually, family members realized the problems were a serious matter that had to be dealt with before they worsened. This is evident in the following quotations:

Yes. So it was the first time that anything had gone beyond just being sort of difficult, like a difficult personality, where he was completely delusional and saying things that were nonsensical. I didn’t actually think there was an illness involved until that moment. Right and then once he started hearing [voices] (Claire).

I was embarrassed to bring friends over because Carter would do really weird things...like we both had rabbits in our backyard and he ended up killing his rabbit. He threw it at the wall. At that point I didn’t want to have anything to do with him. I didn’t want my friends to be around. At that point I realized that it was serious (Sienna).

So Mike sat on our bed and looked at me and...geez what did he say? Basically that they’ll know and they’ll find out and get us or get me...and he’s looking me in the eye. That’s when I knew that he was really sick, like seriously sick (Corry).

Amy, after hearing about one of Joe’s psychotic episodes from her parents, reacted by stating:

“So that was a bit like ‘whoa!’ Something obviously serious is happening.” The increased psychotic symptoms in conjunction with the siblings’ decreased level of functioning in school or

work mobilized families to seek out medical attention. Seeking professional help seemed like the only viable option as most families were not prepared and too ashamed to discuss these matters with other people outside their tight-knit social group. As a result, the extent of time before families pursued a professional opinion was prolonged until a breaking point was finally reached. They could no longer “deal” with their loved one on their own.

**Seeking professional help.** The most turbulent and emotionally disruptive time for the well siblings was when families sought professional help. The most salient emotions were anger, stress, fear, worry, frustration, guilt, concern, sense of loss, and confusion. Others reported feelings of shock, blame, devastation, defeat, denial, and shame. Ethan described his emotions, such as anger, as “those classic feelings”. When Joe experienced one of his psychotic episodes, Jen felt an indescribable “really irrational fear” of what he was thinking at the time. Corry gave an insightful description of his thoughts and emotions when he saw Mike in “full-fledged psychosis”: “I think I was probably paralyzed between complete fear, adrenaline rush to solve problems, total sadness like imagine that your mom died or something like that—just all these things.” Corry compared his extent of sadness when Mike was acutely ill to the mourning process of a death in the family. The persistent and negative feelings mentioned are consistent with the caregiver burden and schizophrenia research which shows well siblings’ experience a great deal of emotional burden that persists throughout their life course (Marsh et al., 1993a, 1993b).

In most cases, persons who are acutely ill with schizophrenia need to be hospitalized (Torrey, 2001). Well siblings described the first hospitalization and diagnosis as life-altering events. Six of the eight families did not know how to access the necessary resources in the community. Five families sought psychiatric hospitalization after numerous previous encounters

with authorities or other specialists (i.e., the police, psychologists, general practitioners, etc.). Ill siblings were typically in the throes of psychosis when they were hospitalized for the first time and promptly required professional attention. Parents, especially mothers, were generally more active in the hospitalization of their loved one. As Tyler mentioned:

I felt my parents were the ones that needed to deal with it, not me, and that I could talk to them and say “you can’t just ignore this.” So I felt that at least there was something to deal with that they could then pursue and they did... My participation was more involved with crisis and what to do with Isaac. I remember having a couple of family meetings where we were trying to figure out whether he should live at home and whether he should move out or what should happen cause there was still, I guess, a concern that we were maybe overreacting, and that there really wasn’t a big problem.

Tyler perceived that being a sibling precluded him from having to deal with Isaac’s increasing mental health problems. However, if well siblings were less involved than their parents, they were still integral to the process of seeking professional help.<sup>39</sup> In some cases, geographical distance prevented well siblings from offering direct help. For instance, Troy mentioned that his mother “took some charge” of the situation and told him and Amy that “this is what happened, this is what we are going to go do” (Amy). “Worried,” Amy asked her mother if she should fly home but her mother said “they had everything pretty much under control.” Ethan was also told over the phone by his mother that Chloe was admitted to the hospital. In some cases, well siblings were less involved in the help-seeking process because of a past history of conflict with the ill sibling. For example, Jen admitted that she had little involvement in having Joe see a psychiatrist because he had been abusive to her in the past and also because of their age difference.

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<sup>39</sup> This partially sheds light on the nature of the sibling relationship in comparison to their parental counterparts. Siblings, although close kin, seem to have less of an obligation to their other siblings, while parents usually take most of the responsibility in matters such as the health of their child. This is consistent with Horwitz’s (1993a) findings that there is a ‘hierarchy of obligations’ at work among family members, especially when a loved one is in need of social support.

Six well siblings were more involved in having their brother or sister admitted to the hospital. This involvement consisted mostly of being part of some type of deception to bring the ill relative to the hospital. For example, Holden recalled when his family decided to hospitalize Audrey: “eventually one day my mom said we have to do this. So, we kind of lied to her and said we were going to a doctor and all got in the car with her and my cousin was there as well to help restrain her if need be and we grabbed her and involuntarily committed her.” On occasion, police and paramedics were contacted to facilitate this process, when the family was unable to manage the situation themselves. Cory mentions how this was the case when his brother Mike was first admitted to hospital:

My mom started talking to North Shore Mental Health describing what was going on and they were planning on having a meeting with Mike and they wanted Mike to see doctors to get [him] committed and I remember because he wouldn't admit that he was sick. We were trying to get him to see the first doctor and told Mike “you don't look healthy, you're getting really thin, [and] you are losing weight.” Something to get him in to get it started so that was starting to happen... I was like “shit” and I didn't know what schizophrenia was but the word popped into my mind. I went downstairs and told my mom and I'm like “mom Mike's got schizophrenia.” She was calm actually she was like “ok.” She left the house I think to scream and went down the street, or something like that and then what happened...then I was at UBC doing some course—an education course—and I had my phone with me because we were trying to get him to the doctor. We were worried about him running away. This all happened in the same week... I got this call at UBC that the police had come and I was like “oh shit” so I ran home and I didn't have a car then. I grabbed a cab and was just like “go as fast as you can, this is an emergency.” I remember coming down in the cab to this cul-de-sac where there was two police cars and an ambulance parked in front of my house. Stopped and the cab driver said like “oh my god what's going on?” I just gave him forty bucks or something like that and got out of the car and he turned around and Mike was just coming up the driveway with the, I guess, RCMP or whatever, and then he got into the ambulance and then I actually cried from the other side of the police car where he couldn't see me. I was so devastated at seeing this happening and so that was Mike getting schizophrenia.

In all instances, the first hospital admission proved quite traumatic for well-siblings. They reported feeling “perplexed,” “upset,” “lousy,” and “useless” in trying to admit their loved one. They also were “embarrassed” that this was taking place and feeling guilty about forcing them to

get treated. Several well siblings said that at the time, they had debated whether it was “the right thing to do.” Families also debated among themselves whether the ill sibling met criteria for involuntary admission under the *Mental Health Act*.<sup>40</sup> These discussions were often prompted by ill siblings’ complaints that their rights had been violated and that they had unfairly lost control over their life.

The ill siblings who were hospitalized received a diagnostic assessment and were treated with medications. The length of patient stay ranged from days to months. The well siblings spoke about how difficult it was not to be in control of their sibling’s care and trust psychiatrists and nurses. None of them had been in a psychiatric unit before. It was a place unfamiliar and daunting for them. It was difficult and disturbing seeing their brother or sister as a psychiatric patient in that setting, as indicated by these comments:

And then when I went and saw her for the first time in the psychiatric ward at Vancouver General Hospital (VGH), she was quite mad about being there and I had a TAG watch on that I got and she was asking whether the watch was the same watch that I always had and thought that I somehow got a new watch. So I think she was still paranoid at the time but it really disturbed me (Holden).

When I saw her in the hospital, she was quite subdued and seeing other people in the [psychiatric unit of the] hospital and it was my first experience going into the hospital [and] it was like “Whoa!” That’s weird.” And she is like sitting there drawing me pictures on her little bed and it looked like she just woke up and was [in a] constant state and I am going like “nice picture” (Ethan).

It was horrible! I think at that point [in the psychiatric unit], what I thought was, he was having some kind of breakdown and it never occurred to me that it would be anything other than just really temporary, that he’d go get some medication or help and that he’d be fine tomorrow. I guess in some ways it still feels like that (Claire).

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<sup>40</sup> There are three strategies to arrange for involuntary admission. (1) Medical certification, whereby the *Mental Health Act* states they must meet the following criteria to be certified: a physician deems the person has a mental illness; the person requires psychiatric treatment in a designated facility; the person requires care or supervision to prevent substantial mental or physical deterioration for the person’s own safety and/or safety of others; and the person cannot be suitably admitted voluntarily. (2) Police intervention. (3) Order by a judge. For more information on strategies two and three, see sections 28.1 and 3.2 of the *Mental Health Act* (Vancouver Coastal Health, 2010).

The first hospitalization solidified how serious the illness was for the well siblings. It also created a rift with the ill siblings, who felt resentful and betrayed by their family members. This process is what Goffman (1961, p. 133–144) calls a “betrayal funnel,” whereby the pre-patient is stripped of his or her rights and liberties and reduced to the status of a mental patient. Several well siblings spoke about worrying that their ill brother or sister would never forgive them for taking a role in having them hospitalized against their will.

At the time of hospitalization, well siblings described seeing other patients who were also acutely psychotic, which further contributed to their realization of how serious the condition was, and which added to their stress. They also mentioned how they and their parents wanted to gain some sense of control over their sibling’s treatment, but that the amount of input they had varied a great deal depending on the staff and the treating doctor.

**Non-adherence to treatment.** After the diagnosis of schizophrenia, well siblings reported that their ill siblings often resisted treatment. They would try to “flee” from the medical facility, or “cover” their symptoms in the presence of professionals or family members in an attempt to mask the severity of their underlying illness, or request a review panel hearing in an attempt to get released early.

When asked about how they dealt with their ill sibling’s resistance to treatment, three well siblings said that they never gave up hope and that they remained very committed to having their loved one see a professional. For instance, Claire recalled how she and her ex-husband finally brought her brother Luke to the hospital emergency department because he was “agitated” and “completely delusional.” The nurses “were not very receptive” and as a result “he bolted.” After a couple of hours searching, Claire and her ex-husband found him “wandering around.” They brought him back and “had to sign to commit him, that this was not his normal behaviour.”

Likewise, Jen explained that it was a “huge struggle” and “fight” to get him to see a psychiatrist and go into a rehabilitation day program at a local university. Amy further elaborated that her “mom and dad had to basically put him in the car [and told him] ‘this is where we’re going!’” Corry recalled when Mike was admitted to the psychiatric unit and got a lawyer “to talk to the tribunal to get himself freed.” Corry explained that the psychiatrist was “really nervous” that Corry would actually be discharged because “it’s hard to commit someone and you never know what the tribunal will say.” Corry talked in detail about how the event unfolded:

So we took Corry to the Lions Gate Hospital and right away he’s back looking the doctor in the eye and saying “I’m fine, I was away for a week. I needed to think.” Looking so confident despite that he stank and had been in the same clothes for a week staring down the doctor saying “what are my rights? Can you keep me here?” And this was a young doctor, he must have been probably not much older than us, probably in his early 30s. He was really nervous to commit my brother. I was standing there with my mom and my stepdad, and my dad wasn’t in town, and I remember looking at this doctor and I’m thinking “if you let my brother go I’m going to kill you. I will absolutely kill you. I have never killed a person before. You are my first.” But the guy was really afraid to commit my brother because he can’t commit a healthy person. It’s bad for your career and he knew things like this. So he was nervous, so my brother wanted to go to Magnolia house which is kind of like a transitional house in North Van. It’s usually for people who are not quite right to be committed or something like that, that it is a few years down the road and you are recovering.

The psychiatrist ended up discharging Mike and he “went missing.” They searched for him with the help of the police, friends, and the media (i.e., broadcasting on a local news station that he was missing and placing his picture in the local papers). Corry described how difficult this was:

This was really traumatic, because we didn’t know where he would go. Would he go to some community in the Northwest Territories and be completely psychotic for the rest of his life and we would not know who or where he is for the rest of his life? This is what was going through our mind... It’s like you lost your dog—“he was sighted here, he was sighted there.” Right... First of all, I went home to call all my friends and everyone I know to look for them. So I just started calling everyone and most of the people I haven’t even told that he was sick. I just didn’t want to get into it; [it] was too emotional. So I’m calling all my friends and saying “look Henry I haven’t told you, but my brother’s got schizophrenia. He’s missing and I need you to help me look for him.” He’s like “ok.” My brother’s friends were going to be arranging a search party for him too, later, after work, but I was leaving like 1:30 in the afternoon or something. So probably within an hour I

had around twenty people at my parents place in North Van and I was freaking out. I had the trail maps of the North Shore cause I am an outdoor guy and I was like “here’s all the places, and if you see him, he’s a big guy. He looks scary but he’s not a fighter. You just punch and you take him out and knock him out cause I’m, like, I’ll do anything. I’d beat my brother to the ground for his own safety if I had to....So we split up in little groups to go try to find him and we’re discussing first where we thought he might go and I was also with my dad just as we were leaving and he was saying something like—my mom was coming up to us a lot—and my dad was saying something about, well you know “you probably won’t find him,” and I remember saying “but I won’t find him if I do nothing. Absolutely nothing will happen unless I try. No matter how futile it is I have to try.” So we all went off and I was running through bushes and stuff and at about 6 o’clock at night, two of my friends was walking through an alley in West Van and they saw him and they called the police and the police got him. I was like “holy shit!” and I was so floored. It was like winning the lottery. You’re like “what?” You don’t really believe it because it was such a shot in the dark. We really felt defeated, it was such a huge blow... but then it was three days later and he voluntarily checked himself in to the hospital which was really cool.

The other well siblings in the study reported similar experiences that were equally frightening and emotionally draining for family members.

The well siblings also spoke about having mixed feelings about the ill siblings’ need to take medications early on, although they recognized this was necessary. For example, Amy empathized with Joe’s feelings and unwillingness to take his meds: “I’d feel mad too if my family made me take drugs and I didn’t think there was something wrong with me.” Other siblings recognized how the medication made their ill siblings feel unlike their “true” selves. They spoke about the difficulties their ill siblings had with accepting the need to be on medication. For example, Corry pointed out that Mike does not like to be on his medication and on as “little as possible to get by.” Thus, “he’s been borderline functioning for a long time.” Just after the time of the follow up interview with Corry, Mike stopped taking his medication and had to be hospitalized again in order to be stabilized. Claire mentioned his brother’s ability to “cover” up his symptoms when he is assessed by a psychiatrist, and that as a result, he is never on the proper dose of antipsychotic. Sienna said Carter constantly would “go off” his medication

and would start hearing voices and talking to himself. All well siblings gave similar accounts of the problems they encountered with their ill siblings' resistance to taking their medication and the relapse(s) that forced the families to hospitalize them. This process resulted in "a revolving door" between treatment facilities and discharge. This is how Tyler described the process:

So, it took a long time to establish and get him into a better situation. It's not as if he...it sounds easy now saying 'well you didn't live at home anymore' but that didn't happen quickly and without a lot of difficulty, cause he would go into the hospital and then go back to my parent's house. Go into the hospital come back to my parent's house and eventually we all decided that he shouldn't live with my parents anymore because it just wasn't working. They couldn't really manage him.

The ill sibling's non-adherence to treatment made the well sibling feel "tired," "parched," and "fed up" although they remained optimistic that one day, they would become willing participants in their treatment. Well siblings eventually became accustomed to dealing with their ill sibling's non-compliance, relapse(s), and were persistent in seeking medical attention whenever this occurred.

**Making sense of the diagnosis.** Well siblings also spoke about point of tensions between professionals and family members. Half of them said they felt excluded from their brother's or sister's care and repeatedly ignored by the professionals. Well siblings expressed frustration with the mental health system for not listening to their perspective. The following quotes illustrate these negative experiences:

That there are obviously some good people but there isn't really a kind of family-oriented viewpoint. They treat the individual, he is an adult so it has nothing to do with anybody but him and his doctor and they don't really involve the other family members. If that's the case, when no family member wants to be involved, I can see that, but when family members actively wish to be involved, then I think that should be looked at and I get the feeling that it's not really looked at....He's well known, like he has been in the system for over 30 years. A lot of the people have seen him so they know him. So I don't want to slag everybody but I am just saying I think there are some real barricades that are up that need to come down (Tyler).

I think there are resources but they're really all over the place. I think the reception I received when I first went to the hospital was brutal. It was uncaring and there was no plan in place. There is now though. I know at Lion's Gate they actually have specific reception set up to handle incoming mental health issues, but I don't think that family suffering from this illness have any idea what resources are available to them and it's really a lot of digging and pushing to try to get things coordinated. It's a mess (Claire).

Tyler added that he blamed the psychiatrists for not returning his phone calls, despite his willingness and availability to be involved. Well siblings used terms like feeling "shut out," "brushed aside," and "left in the dark." In contrast, the other half of the well siblings were "pleased," and "satisfied," with the care their sibling received. These well siblings mainly felt listened to and respected by the professionals who were treating their loved one.

Well siblings spoke of the time it took for the ill sibling to receive the proper diagnosis. They described this time period in terms of a "long time" ranging from a "few months" (Sienna) to a "couple of years" (Ethan, Amy, Jen, Troy). Ill siblings were typically given a tentative diagnosis of psychosis not otherwise specified (NOS) during their first visit and it took a while to rule out other possible illnesses with similar symptoms like substance abuse, or developmental disorder (e.g., autistic disorder). Reaching the proper diagnosis required taking into consideration the patient's history, level of functioning, and behaviour longitudinally (i.e., over a duration), and trials on various medications to determine which ones were the most beneficial. Most, if not all, ill siblings were initially misdiagnosed<sup>41</sup> then rediagnosed with schizophrenia. Holden and Sienna explained that their ill siblings were initially diagnosed with bipolar disorder (manic depression) before receiving a diagnosis of schizophrenia. Troy and Amy recalled that Joe's first

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<sup>41</sup> The misdiagnosis of schizophrenia can be common among mental health professionals. "The instability of the clinical picture in early psychosis such that psychotic mood disorders [e.g., bipolar disorder] and schizophrenia are sometimes indistinguishable, making it difficult to diagnose schizophrenia at the time of first onset of psychosis" (Yung et al., 1996, p. 284). A large portion of patients admitted for hospitalization have symptoms of both diseases. Like bipolar disorder, other diseases present similar symptoms to schizophrenia. In addition, "The symptoms may appear intermittently or may be relatively mild, and the individual may be able to cover up some manifestations of the disease" (Torrey, 2001, p. 91). As such, it is often difficult to make a definitive diagnosis. Professionals may reach a tentative diagnosis until the clinical picture becomes clearer through further diagnostic tests and procedures (ibid.).

psychiatrist said “there wasn’t anything wrong with him” (Amy) and that “you don’t need to worry he’s not schizophrenic” (Troy). Claire was only told by the psychiatrist that Luke was in a psychotic state that needed to be medicated. Well siblings found that the initial lack of clear diagnosis was stressful and it undermined their trust in the mental health system.

Once a diagnosis of schizophrenia was reached, well siblings talked about grappling with understanding the meaning of the term, and the lack of information about this disease. Some well siblings did not know what the term meant at the time, while others had preconceived notions (or misconceptions) of the illness that came from popular misconceptions about the disease. When Sienna heard the term schizophrenia she immediately thought of “split personalities” and how it was “so foreign” to her and “very stigmatized at the time.” Similarly, Claire remarked: “I never thought it was schizophrenia. I didn’t really understand what that is. People don’t know. When I talked to friends about it, they’d say ‘how many personalities does he have?’” Furthermore, the term brought up negative connotations. While Ethan recalled having “no idea” what it meant: “it was not like ‘oh that’s what it was’ or ‘that’s a relief’ or ‘at least I know what it is’ or ‘that’s a terrible diagnosis... don’t say it’s that! It has to be something else.’ I don’t remember having that process. It was more like a dull ‘ok well that’s what they call it.’” Six of the 10 well siblings were not given any educational material by professionals and had to be proactive in educating themselves about the illness.

Common reactions to the diagnosis varied from shock and devastation, to thankfulness and solace. The label at least stopped their guessing as to what it was and allowed them to begin seeing their brother or sister in a new light. In particular, Holden, Mia, and Tyler felt “thankful,” “relieved” and “happy” to have at least an explanation for their ill brother’s or sister’s bizarre behaviour. But Ethan said that he repressed many of his feelings at the time, “probably drank too

much to cope,” and battled depression in his early twenties. Like Ethan, Corry explained how the diagnosis of schizophrenia drastically altered his life:

I think it's turned my life on its side. It took away a ton of energy. I'd say for about three years I was winded from it. Just like being punched in the gut. I was tired; I wanted to eliminate all stress. I didn't want to take on things that would add stress. I didn't want to do things that were hard work. I'm not saying that I didn't want to climb a mountain or stress myself for, but I didn't want to take on a mass of new commitments, like go back and do my Master's or start teaching full time. I didn't want to do these things. That's probably really why I just subbed for a while.

Claire and Sienna recalled that, after the diagnosis, they fantasized about finding a miracle cure. Holden and Ethan too felt deprived of their own personal needs and “alone,” and Holden, Sienna, Ethan, and Troy said they wanted to escape the family. A few well siblings questioned whether they or their parents were partly responsible for the onset of their sibling's schizophrenia, while others felt that they might have contributed to their sibling's disease. Overall, well siblings reflected on the time leading up to the diagnosis and receiving the diagnosis as a turbulent and stressful period for their family, at times strengthening the family, while other times causing distress.

## **Summary**

The onset of schizophrenia was a traumatic time for the well siblings. Prior to the diagnosis, they felt confused by their brother's or sister's altered personality and troubling behaviour. There was variation in the well siblings' initial involvement in seeking professional help, which was determined by the circumstances of each family. The well siblings became much more involved with their ill sibling once they realized the serious nature of the illness. The hospitalization of the ill sibling was described as exhausting and difficult, in part because of the ill sibling's non-adherence to treatment or because families had restricted access to mental health professionals.

Obtaining a diagnosis allowed well siblings to “pick up the pieces” of their broken relationship with their brother or sister, helped them better understand why their brother or sister acted the way they did, and motivated them to seek out information to support their loved one. The diagnosis also changed the way the well siblings perceived and related to their brother or sister, and reconstructed their ill sibling’s identity along medical lines. Seeing their brother or sister in a psychiatric setting reinforced their understanding of seriousness and severity of their ill sibling’s condition. The diagnosis made well siblings realize the permanency of the illness and that they would have to provide care for a long period of time. How the well sibling’s family and their ill brother or sister were treated and listened to by mental health professionals largely shaped their view of the mental health system positively or negatively. After the diagnosis, all well siblings decided to continue to help their parents care for their brother or sister with schizophrenia in some form.

In the following chapter, I turn to the role of well siblings as sibling caregivers and the nature of their relationship after the diagnosis.

## **Chapter 7 : Well Sibling Caregiving After the Diagnosis**

This chapter discusses how well siblings redefined their relationship with the ill brother or sister after the diagnosis. Specifically, I describe how well siblings mourned the loss of their past sibling's self but began to accept who they were today. I further examine the ways in which well siblings transitioned from being a brother or sister prior to the illness, to becoming a caregiver for their affected sibling and what this meant to them. I also compare the level and type of involvement they provide and their expectations for the future.

### **Redefining the Relationship**

The diagnosis marked a drastic change in the way well siblings related to their brother or sister. Prior to the diagnosis, well siblings had a certain idea about how they expected their relationship to develop with their ill relative, and expected to be sharing life stages such as marriage and having a child, for example. For instance, two well siblings noted that, before their brother or sister became ill, they expected he/she would someday get married and that they would be part of his/her wedding plans. Once their brother or sister became ill, these well siblings realized that this was an unlikely expectation and realized that their relationship would evolve differently and primarily as a caregiver. For example, Holden spoke about how he always had pictured his relationship with Audrey to be reciprocal and affectionate, yet his view quickly changed when she became ill: "My expectations of what the relationship might have been in the future years, based on our childhood, suddenly changed overnight" (Holden). Siblings provided like accounts of how their great expectations for their ill brother or sister were tarnished as well.

Well siblings described their ill brother or sister as not resembling the brother or sister they once knew so intimately growing up together. They attributed changes in personality and

behaviour to schizophrenia and the side effects of the medications. They used several terms to describe their siblings' current state, such as "being lethargic," "lack of motivation," "more subdued," "simplified," "introverted," "reclusive," "tired," "demoralized about things," and "very shy." Other descriptors included: "less happy," "more worried," "abusive," "aggressive," "manipulative," "not comfortable to be around," "strange," and "self-centered." Although most of the terms were negative, well siblings also noted positive characteristics, such as "being very nice," "in some ways more mature," "more stable," "a lot calmer," "developed into his own a lot more," "more confident," "unique," and "jovial."

Well siblings changed their perceptions of their brother's or sister's past "healthy" self to a "sick" self after the diagnosis of schizophrenia. The diagnosis allowed family members to attach a label to their loved one's deviance or what Scheff (1966, 1975) calls "residual rule-breaking" (p. 34). Residual rule-breaking behaviours are forms of deviance for which there are no initially explicit labels.

Scheff (1966, p. 32) argued that once a person has been labelled as deviant, he or she will internalize these meanings and perform according to the expectations that others have of him or her based on the label that is applied. This process was evident to some extent in the way well siblings described their ill siblings in relation to their diagnosis and their illness. Well siblings clearly distinguished their ill siblings in terms of an "old" and "new" identity. For example, Holden stated: "So there are only a very few occasions where I can actually be fulfilled on a really good level and see her true self or identity of who she is now and learn to accept that. And I think that is another hard thing to do, to accept who she is now and is different from who she was, and she will never be the same and try to go on." Likewise, Holden spoke of Audrey's "true self" in terms of her identity before she was labelled as "schizophrenic." This process of

labelling was marked by a reconstruction of the ill sibling as another person quite different from the sibling prediagnosis. However, some siblings spoke about their sibling as being the same person and described the changes in terms of the illness taking over their brother or sister. For example, Corry described his brother Mike as being the “same guy” but “handicapped.” He added: “it is the illness you are seeing.”

Lively and colleagues (1995) described how well siblings’ perceptions of their affected loved one revolved around the theme of loss; he reports siblings describing their brother or sister as “a broken person...a shell of what she once was” or “someone who has lost his entire personality” (ibid., p. 230). Well siblings often described the negative symptoms of schizophrenia and the side effects of antipsychotic medication, which produced a hollow quality to their ill brother’s or sister’s personality. Comparing who Chloe was before the onset of the illness with after the diagnosis, Ethan said that there was less of a “spark through her eyes” and as if “the life had been sucked right out of her.” Siblings described the ill sibling as having much less of a social presence. The illness had taken their “spirit” or “soul” which well siblings said that they were grieving. Holden described Audrey as almost “empty” and “lacking depth” compared to how she once was, and added that there were periods where you could glimpse into the remnants of her past healthy self. He pessimistically noted: “she has transformed into someone else now, like a different type of person and you can never get back that other person who has a lot more substance to them and complexity.” The other well siblings echoed Holden’s sentiments regarding the changes in his sister to basically becoming “a more simplified version of her past self.” Throughout the interviews, well siblings reified the disease as having a will of its own. They spoke of how the illness had “attacked,” “consumed,” and “overtaken” their sibling. They said the illness allowed their ill siblings to sometimes “get off the hook” for their

deviant actions. Consequently, there was a sense of loss for the responsible and competent brother or sister they once had.

The change in status for the ill sibling was further compounded by their inability to engage in the activities they once enjoyed in their younger years. Well siblings said that hobbies such as rugby, painting, or playing music that were previously enjoyed, became too difficult and stressful for their ill brother or sister. Past hobbies were replaced with simpler activities such as watching TV, smoking cigarettes, listening to music, or swimming at a public pool. The symptoms of the illness (e.g., impairment in cognitive functioning) also significantly reduced their ability to handle certain activities, especially if they involved a great deal of social interaction with others. For instance, Amy mentioned dragon boating was a past source of enjoyment for Joe for “a really long time, but when the illness kicked in, he got a really severe paranoia of water. So he couldn’t paddle anymore, but he was like on the competitive team. He went to Hawaii and paddled competitively.” At the extreme, Corry explained Mike was “housebound for the most part” and “the more sophisticated types of thinking activities, he doesn’t do anymore.” These inability were disheartening for well siblings. The ill siblings’ identities had been largely associated with these activities; they defined who they were as individuals and how others perceived them. Ethan imagined what Chloe could be capable of doing if she were healthy: “She’d be able to be mobile. She could drive. She could come over here [to where he lives]. She could cross a bridge. She could go out to a restaurant without worrying about stuff and it wouldn’t have to be this particular restaurant because other restaurants have this or that about them, right? So, just even going out and about doing stuff is hindered.”

The illness also isolated the ill siblings from past friendships. In many instances, the family became the only support system that remained close to them, particularly their parents. Ill siblings made new friends with individuals who also had a SMI and who enjoyed similar activities and peer groups. This was one of the activities that allowed ill siblings to feel more accepted by others. Goffman (1963, p. 28) argued that individuals who share the same stigma and thus can perceive themselves as similar, are also likely to provide support to each other. This process also occurred among the well siblings who formed tight social bonds with other siblings of people with SMI. It allowed them to share their personal stories with others who could understand and not judge them. Four of the well siblings reported that having an ill sibling resulted in the loss of “childhood” friends who began to distance themselves. This process illustrates what Goffman (*ibid.*, p. 30) calls “courtesy stigma.” Because well siblings were related to the stigmatized individual, they too shared the discredit that their loved one faced. These well siblings said they learned to cope with being stigmatized and maintained a close connection with their ill sibling. Two of them mentioned how their other siblings had distanced themselves from the ill sibling to avoid losing friends.

Well siblings came to the realization that “it is what it is” and learned to accept the newly formed bond with their sibling that developed within the illness. They sought comfort in the hope of future improvements and of seeing the return of some of the normalcy that was present when they were originally growing up together. For example, Claire recognized the chronic nature of the illness and yet tried to stay hopeful for a better treatment to arise: “Whereas I mean, it’s easier if you’re not the person affected to accept that this is probably the reality for him permanently unless something comes out differently medication-wise.” Claire wished that a new drug might be able to cure the illness rather than just treat it. All well siblings hoped that a cure

might be found for schizophrenia. Acceptance also came with not placing the blame on anyone for causing their loved one's illness, as expressed by Tyler: "one of the things we talk about among the families is it's [the illness] not your fault and I totally believe that and I act on that it's not anybody's fault. It's not my fault, it's not my brother's fault, it's just the way it is and there's not guilt."

Living day to day was a mechanism used by well siblings to minimize their sadness over the chronic nature of the illness. It also allowed them to enjoy the few positive moments with their sibling and not dwell on the setbacks in the course of his or her illness. As Corry said, "I think about what he needs at the moment and that's just greater engagement with the world, so when I see him doing that, I am happy." In contrast, Sienna was not optimistic that Carter's health would drastically improve, but stressed the importance of being content with him in the now:

I think we need to deal with him the way he is now and not try to make him better, I guess, and my mom is trying to get him off his medication and I am thinking that's the wrong way to go. It's funny that I say that though, that I know he is not going to get better, but that I get mad at him for the things that he does that he should know are wrong. It's a bit ironic, I guess.

The process of becoming a well sibling caregiver also meant acknowledging and shifting their expectations of what their affected sibling was capable of. For instance, when Audrey said she wanted to become a marine biologist, Holden informed her that she would have to complete a lot more schooling. He thought that this was an "impractical, silly, and absurd" idea for her to have, considering her present inability to perform even mundane daily tasks, and considering her unsuccessful past with school. He suggested that she set some short-term goals, such as enrolling in a few courses in community college first, to see how she does and to "test the water." Claire told of how Luke wanted to become a matador, but believed that this was a "grandiose thought."

She went on to explain, “I guess it’s like anyone with a new idea. You get excited about it and then as the kind of reality of what’s involved in doing it sets in. I know Luke’s like that—he’ll get excited about something and then it’s not practical for him to do it.” Other well siblings realized that their ill brother or sister might have difficulty attaining his or her goals as these quotes portray:

I think, realistically, he could work towards having his own apartment and relationship because he is in one now, which I mean it’s hard because he’s only seeing her about once a week and finds that stressful. So the relationship thing, I am not sure how that could play in, but I know that is something he wants, so I hope that for him (Jen).

I mean, of course he doesn’t have a girlfriend because he has been sick as a dog. We want him to have a job that he likes, have those types of things. Although, I know that’s not in the immediate future (Corry).

Well siblings tried to set small yet attainable goals for their ill sibling to reach. They had to make decisions regarding how much “pressure” to put on their ill sibling and when to “back off.” For example, Claire once bought a car for Luke in order to help him deliver pizzas. Instead of using the car for his job, he drove the car to pick up drugs and eventually crashed it. Claire further discussed how she felt about the incident: “I often feel like in my participation I get a little over enthusiastic and put him in a position where he can’t easily come back from it. It made me feel a bit like I pushed him to be somewhere where he wasn’t ready to be. So that’s why maybe I am, like, a little more measured in my offering him help.” Well siblings recognized that their ill sibling’s improvements in functioning were a slow and gradual process that would not occur overnight. Corry described Mike’s recovery as a “two steps forward, one step back” process. He also stated:

I try to keep it simple, and this is where he is, and this is like the next step he needs to get to. So, I feel that the goals we are setting are reasonable. I try not to get too far ahead of myself. I really believe that he can go a long ways. I’m also convinced it is not going to be quick. Maybe I am hopeful to the end of my days. So be it if it turns out that way, I guess. But I’m not crying over a particular stage and hoping he gets there.

They set their expectations in relation to what they wanted for their ill sibling. Generally, they hoped their ill sibling would have some form of independence, perhaps living on his or her own, having employment that is rewarding or at least an activity (e.g., volunteering) that they can take pleasure in, and having meaningful social relationships with others. Basically, all well siblings wished that their ill sibling obtain a certain level of “happiness in life.”

By shifting their expectations, well siblings learned to appreciate the “little things” and small accomplishments. These were a source of satisfaction, hope, and enjoyment for them:

Carter is doing beading, bracelets and stuff like that. I think that’s something that they’ve given him to do at the hospital. This last birthday, he gave me a bracelet. He’s never really given anything ‘cause he never had any money or cared about it. I just felt when he made me this bracelet and I almost wanted to cry, you know. I just couldn’t believe it. And it had a little card on it and he wrote my name on it and it was just amazing (Sienna).

I’m super proud of Joe. I just remember he could not go into a Safeway because he thought people were looking at him. Now he’s going to clubs with girls and he has a life without me. Before it was just depressing... like disappointment after disappointment. So the fact that he’s having fun and more social and interactive is good (Troy).

Any progress made by ill siblings was viewed by well siblings as an improvement in functioning. Jen commented that it was a “huge deal” when Joe went shopping and bought Christmas presents this year by himself. Similarly, Amy expressed that “we take for granted [the little things] like just basically studying or taking a test; he works so hard to do the things that he does and that’s really cool to see.” Ethan gave Chloe an incentive by telling her that if she goes to the gym for a month, he would give her a hundred dollars. She “has kept it up on her own right” and Ethan took pleasure in her initiative to “stick with it.” Holden also said that there are “inspiring moments where she will get up really early in the morning and shock us by doing something, saying something or listening or she will work toward a great accomplishment and be motivated.” While these small accomplishments may seem insignificant and “nothing special” to

others, well siblings and family members use these as signifiers of how well they were doing over time.

Well siblings also compared their relationship with the ill sibling to their relationship of others with healthy siblings. Ethan remarked: “I would see other friends with their brother or sister and seeing, sensing, feeling a loss of not being able to have that certain relationship.” He went on to say “I can’t talk to her about certain things and it’s different from having a well sibling, I can imagine. So I imagine that has changed. That’s a loss. If you look at other people with their relationships with their siblings and they can talk to each other about things, and talk about parents and life and that sort of stuff.” Sienna similarly stated: “Sometimes I see my friends and their brother or sister and it would be nice to have that.” Tyler wished that he could just have a normal conversation with Isaac, instead of discussing topics that are centered on his delusions that “do not make any sense.” Ethan speculated on what it might be like to have a sister who was not ill:

Her comfort zone I think would be far more expanded if she didn’t have the illness. She’d be able to be mobile. She could drive. She could come over here. She could cross a bridge. She could go out to a restaurant without worrying about stuff and it wouldn’t have to be this particular restaurant because other restaurants have this or that about them, right? So, just even going out and about doing stuff is hindered.

Likewise, Holden envisioned that, if Audrey did not have the illness, they both would have had their own families by now and would have spent a great deal of time with each other’s relatives annually. He also expressed that she would be his “big sister” again, being consistently “there for him” should he be in financial or emotional need but conceded that this would “never happen.”

## Dealing with Dependency

In sibling relationships, there tends to be a relative balance of “give” and “take.” However, because of the chronic and debilitating nature of schizophrenia, the ill siblings became highly dependent on their siblings to assist them with the tasks and responsibilities of daily living. Typical of other well siblings as well is the comment made by Holden about Audrey, that “she is very needy and requires supervision” and as a result he “is forced to manage many of her everyday tasks.” All well siblings described having to make a conscious effort to build a relationship with the ill brother or sister and become more involved in his or her life. Caregiving necessitated becoming involved on a daily, weekly, or monthly basis. They invested far more time and energy into their relationship, but received little in exchange from the ill sibling, as indicated by the following three comments:

I initiate more, although just the past month he has been calling me. It is the first time in my life that, a month ago, he called me on the phone cause before I always lived at home, but ever since I moved he never called me because he was sick. So he is starting to initiate, which, well, I was first off surprised getting Mike’s call. It was kind of cool but how it’s changed is really hard because, when he got sick, we were both living at home. You know you grow up across the hall from someone. And now I take the effort to be involved in his life. So I think that it’s quite a difference. We are not contributing equally to our relationship, although I don’t expect that. I am the one that will make sure that I am there hanging around even though he’s called me a few times. I am still the one that will show up and ask him to hang out or to do something (Corry).

In terms of involvement, I think the nature of it is different. As I was saying earlier, it has been more one-sided, whereas I can’t talk with her or interact with her as an equal—not in a bad way, just that’s the reality of it. Before, I probably could but I think if she were well, I would probably talk with her the same amount but just be more about different things and probably have a level of support that she could give me right now (Ethan).

Like I said before, the dynamic of the relationship I think has changed where it consisted of a mutual relationship and obligations, but I think now it has become more of a one-way street in the fact that I will go out and help her (Holden).

Caregiving responsibilities included attending to the sibling's needs for food, water, shelter, and clothing. Well siblings also provided support and attended to their siblings' social-psychological needs such as socialization, life skills training, and educating about the illness. There was a range in the amount and type of activities well siblings participated in depending on the severity, course of the illness, and how much support was therefore required. Gauging on how well Luke was doing at the time, Claire "made an agreement with herself" to call him daily and visit him in the hospital when he is in need of medical attention (e.g., suicide attempts) as often as she can. In all cases, well siblings managed the tasks that were needed to help them with functioning, including monitoring of medication, helping with chores, and dealing with mental health professionals.

Well siblings primarily considered these caregiving activities a way to connect and reinforce sibling bonds with their affected loved one. While they thought spending time with him or her in a supportive role was a source of burden, it allowed well siblings to nurture their relationship and get closer. A few siblings even stated that they did not see being with their sibling as a source of burden, but rather as something they took pleasure in and did out of kindness.

Caregiving for the ill sibling became the focal point of family communication. Specifically, family members discussed how they thought the affected loved one was doing, what needed to be done to improve his or her overall functioning, and about general gossip regarding their ill relative. This affected the relationship between the well siblings and their parents and was an added source of stress for them. Caregiving for their ill relative was a sensitive, opinionated, and "draining" topic to discuss among family members, and disputes often arose out of their opposing beliefs pertaining to how they thought the treatment plan should

unfold. Commenting on the nature of her relationship with her parents, Mia mentioned that most of her conversations with them were about Ian and felt “a disconnect” between herself and them as a result. Corry, on the other hand, expressed that his talks with his parents were constructive and beneficial in building their relationship, using the topic of caregiving as a catalyst to spend more time together, despite its focus on Mike. Caregiving became a common activity for them which they could share and trade ideas on strategies and coping techniques. He reasoned that, because he and his mother were teachers, they were able to communicate and resolve conflicts effectively.

The attention given to the ill siblings by their parents left some well siblings feeling neglected, and this was a frequent source of resentment toward the parents and ill siblings. In Joe’s family, all three well siblings were quite vocal about the great deal of affection that Joe required, and adamant that it caused rifts in their relationships with their parents. Jen and Troy felt that, as the illness emerged, Joe required more attention: “Joe used to always get a lot of attention, even when I was younger just before he was diagnosed because, obviously, there was something off and he just needed that kind of extra attention and that hasn’t changed” (Jen).

Well siblings eventually realized the need for their parents to devote this attention to their ill sibling and began to accept it, as illustrated by this quote: “Back then I was very resentful, but now I realize like how much of the attention it goes toward the ill child” (Sienna). Holden expanded on this issue:

I felt Audrey always, when we were younger, received quite a bit of the attention because of her behavioural problems at the time when she was a teenager. Now, I am not sure if that had to do with her getting sick with the illness and therefore my parents and I were trying to figure it out, or she was just like that. But even now it is similar in the fact that she gets most of the attention from my parents due to her illness and all the supervision that it accompanies. I understand completely though that she needs this attention, so I do not resent my parents or anything for the amount of time and effort they put into her rather than my issues, problems, etc. It’s just the way it is I guess (Holden).

The lack of reciprocity in the well and ill sibling relationship was also a cause for concern. Well siblings felt that their ill siblings were continually “stuck in their own minds or [preoccupied with their] thoughts.” They were described as incapable of taking the role of the other as indicated by the following comment from Ethan: “It’s all about her now... she likes to talk about herself... [and] the topics center around her.” Tyler also volunteered the following comment about his brother:

He really lives in his head. He kind of notices things but everything is related back to him. So when you go talk to him, it’s always about his latest thoughts on whatever. He’ll say ‘how are you?’ but he is not really interested in the answer. He just wants to tell you his latest delusion that he has. Now it’s about how he thinks my sister is going to be murdered.

This self-centeredness impacted the way well and ill siblings interacted. These interactions primarily consisted of well siblings asking the ill sibling various questions about their life, giving advice, and guiding the topic of conversation while avoiding sensitive issues. Ironically, as a result of caring for their ill brother or sister, many well siblings built a stronger bond and became much closer.

### **Reversing Roles**

As caregivers, well siblings felt they were assuming more the role of parent than sibling. Prior to the illness, the siblings related to each other more or less as equals. However, the relationship began to evolve and become defined primarily in terms of dependency and, as such, acquired a more parent–child-like quality. This role reversal is illustrated in this comment by Ethan about his relationship with Chloe:

So in that sense, my role [has] become more of a provider rather than a peer. I think that’s what I mean when the relationship remains not sort of equal, that’s what I sort of mean too. It’s not the same as having a buddy chat with my sister. That’s part there but it’s, I can imagine, being more.

Well siblings compared caring for their ill sibling to raising a young child. Amy felt like a mother to Joe. She always worried how he would react “bringing him out” and “always thought about all the possibilities that could happen [to him in social situations].” They expressed feeling obligated and somewhat responsible to watch over and supervise their ill brother or sister and care for their welfare and well-being. Two well siblings stressed the importance of “keeping an eye” on the ill sibling. Even when the ill sibling was not present, well siblings experienced a “looming presence” of worry for their ill brother or sister and guilt over not being around to look after him or her, as illustrated by Tyler’s comment: “Like when I went off to Toronto two summers ago, and it was not a good time and I, in some ways, regret going because my brother just went right off the rails and was living off the streets, and I might have been able to help if I was here. It definitely looms over me that I have to keep an eye on him.”

Siblings repeatedly mentioned that their ill sibling exhibited childlike personality traits and behaviours as illustrated by these comments: “he is like a 9-year-old kid,” “like a spoiled child” (Sienna), and “baby-like” (Holden). Troy said interacting with Joe was as if he was “taking care of a toddler.” Despite this, he further contrasted the way he hung out with Joe on vacation to how his older sister Amy perceived being with Joe at the time, “I spent a ton of time with Joe in Hawaii and I had a great time, whereas Amy would take it as ‘more like oh I have to babysit him.’” Corry stated his career choice as a teacher allowed him to “look at young people’s development and it fits in quite closely to where he [Mike] is, where he is going, where we want him to go, [and] how we can work with that.”

Reversing roles meant well siblings began teaching their ill brother or sister basic life and custodial skills, such as cooking and cleaning, that were typically expected from parents socializing their children toward independence. They assisted with mundane and simple

everyday tasks that were often tedious and time consuming, like “making a grilled cheese” (Jen), “wrapping Christmas presents” (Jen) “bringing him out in the snow” (Amy), “doing the laundry” (Holden). Well siblings described ill siblings’ disposition and mannerisms as resembling that of a child: “get mad,” “yell,” “stomp around,” “mope,” and “whine.” As a result, well siblings had to learn how to “parent” their ill sibling on a “trial-by-error” basis.

This parental role included dealing with the child-like and bizarre behaviours that added to the stigma of mental illness because of their visibility. According to Goffman (1963, p. 47–49), the amount of discrimination and the stigma(s) attached to the individual and whoever he or she is “with,” is heavily influenced by the “visibility” “obtrusiveness,” and “perceived focus” of the social blemish. Schizophrenia may not be immediately visible to others, yet can be uncovered by psychotic and inappropriate behaviour that suggests SMI. Sienna, for instance, dreaded bringing Carter out and became highly agitated by his bizarre conduct around strangers:

Well, sometimes I feel like we should be doing more together, but just recently, and I told my mom this at Christmas, ‘I can’t handle going out with him because he touches people.’ So when they’re walking by or if we’re in the mall, he’ll go up and touch people or he’ll go up to them and ask them if he can shake their hand and for some reason he’s fixated on women with babies and that’s the worst thing because I’m like ‘Oh my god that’s the worst possible person you can walk up to and touch!’ They’re like holding their baby in their arms. I get so angry and embarrassed that I don’t know how to handle these things...Anyways, so it’s hard for me to do activities with him...It’s funny because my boyfriend deals with it really well. Like if that ever happens and he’s with me, he will go up to the person and say ‘Sorry man’ or whatever and then just grab my brother and kind of walk away and I will be like ‘Carter why did you do that?’ and I am yelling at him and I am so angry. I’d like to learn how to do it in a better way, but think when you are so connected with your family, right, so you want them to behave correctly. It’s just it’s harder, I think.

A simple activity, such as taking Carter out in public, became a complicated and nerve-racking ordeal for Sienna. All well siblings told similar stories regarding social outings with their ill

sibling. In this context, well siblings attempted to appear “normal” around others, trying to conceal the ill sibling’s illness, and the stigma of their problematic behaviour.

Just as children need adult guidance and supervision, the ill siblings tended to require direction and control. At times, the ill sibling’s childlike disposition and mannerisms forced well siblings to take on a disciplinary role, which typically the parents conceded and exercised authority over: “He was raised the same as I was. He does know what is wrong and what is right...and I just think there needs to be some form of punishment for what he does” (Sienna). They subscribed to the notion of “giving tough love.” Some well siblings felt their parents were far too lenient with their ill siblings and “let them do whatever they want.” Parents typically did not punish them for their wrongdoings, excusing the inappropriate conduct on the illness. Sienna gave an example of how Carter tried to get his own way: he would manipulate the situation and “pull” on his family members’ “heart strings”:

If you say ‘no we can’t go to the mall right now!’ he’ll start crying, right. And it’s fake crying and you know it’s fake crying and you can just go ‘it’s not going to work on me.’ Then he stops and I think what else is he going to do? And he leaves and then he comes back and he’s like ‘mom just told me that you have to take me to the mall,’ and I am like ‘well when did you talk to her?’

Acting out is common among youth rebelling against their parent’s authority and testing their limits in order to achieve a desired outcome. Other well siblings spoke of similar strategies used by their ill sibling in the attempt to take advantage of other family members to get what they wanted. Parents were found to “give in” to the demands of their ill child, perhaps because of guilt around the illness. Well siblings “saw through these acts” and felt that the ill siblings should be given more limits on what is acceptable behaviour. As a result of parental lenience, some well siblings felt they had assumed more of a parental role than their own parents.

## Living My Life

Although well siblings provided support to their affected brother or sister, they also needed to live their own lives. Well siblings tried to find a balance between caregiving for their ill sibling and maintaining their own independent lives (away from their ill sibling). For example, Corry compared his life to his brother's own development:

I mean I am happy my life is moving forward. Because sometimes I imagine that one day we could buy a house together, let's say, to start out with and things like that. So that of course, hasn't evolved. I mean, it's been for him, getting sick, it's been a long time right, so I have become the adult, got a few grey hairs, and he still lives at home. I think perhaps, it is four years difference between us, I'm older he's younger. Like that's that four years is becoming more and more and more years. Right, it's not like I have four years of experience—it's like a decade of experience. I guess that's the best way that I can describe it, you know. When I look at him, he's just got a lot of catching up to do.

All had their own families, relationships, responsibilities, priorities, and life pursuits that they wanted to satisfy, which did not directly involve their ill sibling. Well siblings attempted to strike a balance while trying to maintain their independent lives. Yet it was rare for them to reach this “equilibrium.” They often had to reassess how they were going to “juggle” their responsibilities and attend to the needs of their ill siblings. Sometimes, well siblings focused on their own personal issues and needs that had nothing to do with their ill sibling, while at other times, they would become overly involved with taking care of their ill sibling and helping their parents needs and the demands of caregiving. This balance would shift depending on the severity and course of their affected brother's or sister's illness and, as such, how much support he or she required at the time. Amy, Jen, and Troy's ill sibling Joe was functional and independent at the time of the interview. Therefore, he did not need a great deal of assistance from his well siblings. On the other hand, Claire's ill brother Luke was having difficulties and frequently relapsed and required hospitalization. As a result, Claire was highly involved on a day-to-day basis to help

support him. This directly influenced the balance in her life with respect to her own job, family, and personal responsibilities: “whenever he’s having more problems—like if he’s in the hospital—then of course it affects me because it has to become a daily part of my day-to-visit with him, which is fine—like I don’t know/mind spending the time, but it’s disruptive emotionally to go everyday through that experience.”

The siblings described needing to rest, “recharge their batteries,” and not become overwhelmed with the demands of caregiving. Jen explained that she left for university out of province after Joe was diagnosed and at a later stage in his recovery. She “wanted to get away” not necessarily from Joe, but from the family drama and to “gain [her] own independence.” Sienna insightfully commented, “I don’t know, at times I feel guilty and my New Year’s resolutions are always, say, spend more time with Carter, but other times I feel like I need to have my life as well apart from him because otherwise I could become like my parents, where it just becomes all-consuming. So I think it’s really healthier to just have that distance you know.” It was healthy for well siblings to have a certain amount of distance from their ill loved one.

Many well siblings felt they had to overcompensate for their ill sibling’s lack of success and progress. They did not want to be a “disappointment” to their parents. Lefley (1996) mentioned that many siblings experience the “replacement child syndrome.” Siblings become overachievers and strive to be the ‘perfect’ child in order to spare their parents from more suffering for the ‘lost’ life of the ill brother or sister. All siblings mentioned experiencing a great deal of guilt and pressure: “I have more pressure to succeed because there is only the two of us. My mom’s like ‘well I lost one so all my hope is in you.’ She says that it’s kind of true, so there’s a bit of pressure” (Sienna). Like Sienna, Ethan discussed how his role has changed and feels “a lot rests on his shoulders in terms of his parent’s hopes and achievements.” Holden

considered himself an only child in the way his parents assumed that he should manage most of the housework and daily chores, excusing Audrey because of her illness: “But now I have just come to accept the role that I am one sibling and mainly almost the only sibling that is expected to have some responsibilities from day to day.” He added:

Now that she is ill, a lot more responsibilities are put on me to kind of help out with things and her, and since I kind of have that responsibility of being the older brother to her and trying to help her with her life, and kind of all of us chipping in to create a good positive family environment...At the same time as her not being in university, I am the kind of only sibling left who has some sense in becoming successful in the kind of societal sense, where I will have a car, a job, a wife, [and] get married.

Likewise, Tyler described his role as the older sibling and what expectations are involved in this role, especially with a sibling with schizophrenia:

I don't know whether a lot of older brothers feel they are the ones who ultimately their parents look to and call on. I have always been like that [the dependable one]...and I'm the one who has, in my family, the only one who has a steady job. Well not true. My brother is his own employer; he is a carpenter and does his own thing so he works steadily, but I am the guy who has done closest to the path that your parents might think you should do eventually. I mean I have worked here now for over twenty years. So my role has changed definitely. I am more the person they think of to call [on].

While the siblings in this study chose to assist in caregiving, they also stated, to their chagrin, many of their other healthy brothers and sisters had completely severed all ties with their ill sibling and did not assist with caregiving. It is important to recognize that “the decisions whether and how to be involved with an ill sibling [disturbed], depends on the extent to which the well one identifies with the parents and with the sibling” (Bank & Kahn, 1982, p. 238). There is evidence of this by the range in the level of support reported by well siblings among these families. There were several reasons to explain this lack of involvement including age, personality differences, geographical proximity, their beliefs surrounding the illness, and stigmatization. For example, Tyler's brother had a hard time accepting the fact that Isaac has a

SMI and believed Isaac uses his illness as a “crutch” in order to continue his drug abuse and way of life, being unemployed and free of responsibility:

I don't see too much of a relationship when we get together for family gatherings; they interact in some ways. I know Isaac wants/would like to be more involved with Pete but Pete doesn't really want to be too much involved. I mean they both drink too much. He's definitely an alcoholic and so he smokes. So those two guys smoke, so they sort of have the smoking tobacco and I know Isaac has his crack and Pete has his booze. Those sorts of things. So I think Isaac feels kind of close to Pete and, at one point when he was looking for a place, he was actually wanting to move in with Pete and Pete was unhappy to do that. So yes. They have a kind of—like I said earlier—Pete thinks Isaac needs to pull it together and quit fooling around and he would be a lot better off (Tyler).

Others were partly involved but did not provide the amount of care their well siblings provided.

Claire admitted that her other sister did not interact with Luke when she came home for holidays because of personality conflicts. Claire had “animosity” toward her sister because of her unwillingness to be more involved in Luke's life. Tyler said “I get mad because my sister and brother never go see him. Then I go ‘why am I always doing it?’ It's like a push and pull!”

In some cases, conflicting tensions arose in the well sibling's own family. For instance, Tyler's amount of devotion to Isaac came at the expense of occasionally not spending enough time with his own family and dealing with their issues and needs:

My wife's feelings are complicated; she supports me, but at the same time, our son is such a handful that she worries that I need to be taking care of our own situation and [wonders] why don't my siblings get more involved. Why are you always going over to the hospital? Why don't they go over to the hospital? Why are you doing this? So that's an interesting challenge. It is a point of tension.

How, then, did the well siblings in this study become caregivers instead of the other healthy siblings? Their willingness to assume this role was due to a combination of factors. Well siblings felt it was their role as a “sibling.” Family duty and obligation to help out their loved one pressured them to take care of him or her to some degree. Interestingly, it was difficult for well siblings to verbalize what “being a sibling” meant to them when I probed further. They did not

necessarily want to take on this role, but knew that it was partly “up” to them to share the caregiver burden with their parents because there was a lack of available options. Powerful emotions, mainly affection and care, but also guilt, motivated them to assume responsibility. Questions such as “if I did not help, who would?” (Holden) occupied their minds and heavily weighed on their decision on how much involvement they wanted to have. The factors involved in deciding to become a caregiver were highly circumstantial and multifaceted depending on the social context and individuals involved. In the families where there were only two siblings, it seemed their sense of familial obligation was more influential in impacting their decision to care. As they were the only other sibling, there was no one else to help assume the caregiving role. Consistent with past research on sibling involvement, parental pressure and expectations were also noted by siblings as factors in determining their level of care. What led some well siblings to become more involved while others not as much, was additionally attributed to their personalities, attitudes, closeness toward the other family members, and access to other available supports.

Well siblings learned to compromise their own needs currently and in the future in order to look after their ill sibling. This quote for Tyler illustrates this point:

Or also, the other thing is that I also volunteered with the North Shore Schizophrenia Society to help teach a course because I got help through that and so I am sort of, felt I should give back since it helped so much. So that’s another thing, I will have one night preparing and another night teaching. That’s another thing, right? I mean, that’s not strictly dealing with my brother, but you know what I mean. So that’s what her [his wife] concerns are, but she always supports me when push comes to shove. She is always there. She’s also been really clear on the fact that he is not going to live with us. That’s a nonstarter. So, we will have to find him some other housing. I tend to agree with that; I don’t think it would be a good thing ultimately for anybody—for him or for us.

Similarly, Corry said he decided to stay in Vancouver because his brother was ill.

Otherwise, he would be living in Europe somewhere. Families accommodated the ill sibling and

gauged if he or she could manage certain people and situations, depending on how “well” he or she was doing at the time. Well siblings talked about their parents, and particularly their mothers, as providing most of the support. Societal expectations surrounding traditional gender roles and family caregiving explain this choice. Lukens and colleagues (2004), in a study of well sibling caregivers, note that the variety of responses and involvement by siblings is not surprising, “given that societal norms and expectations regarding caregiving responsibility between siblings are more vague and ambiguous than between parent and child” (p. 490). Another study also suggests that siblings’ obligations are less explicit and not as demanding as their parents’ caregiving responsibilities (Stalberg et al., 2004). In this study, mothers were thought of as caregivers to whom this role came naturally, because they possessed an instinctive and nurturing quality. As Holden explained:

I think probably [his mother provides most of the care] because traditionally she’s always had that role as the mother; it’s come natural to her as a mother. I think a lot of times my dad, when we were younger, he was working and he travelled quite a bit, so that would come less natural to him. So I guess I would say that, because she has that motherly instinct and motherly role, as well as I think that she has invested a lot of invested time and interest in her own child and in her only daughter (Holden).

Corry reasoned that his mother is “more emotionally involved than the rest of us” because it is her role to be involved in the lives of her children and wishes for their success. He further compared “not sounding callous here, I am very involved as well, but whatever I am, she is double.” Jen also noted that her mother has “always kind of taken on that caretaker role with all of us and I think just especially with Joe because he has schizophrenia.” When parents were separated, the ill child primarily stayed with the mother and remained in her care. It seemed many well siblings assumed it was the parents’, and especially the mother’s, right and responsibility to take care of their child, ill or otherwise. Parents’ geographical proximity to the ill child (e.g., residing in the same household) was also voiced by well siblings as increasing

their involvement in the care of their child. Additionally, the intimate nature of the ill child's relationship with one of their parents (i.e., preference to whom they seek support from among family members) was noted.

Unlike parents, who are expected to care for their children, siblings are seen to have less of an obligation to each other when parents are available and capable to fill this role. Many well siblings confirmed this by noting that, while they feel obligated to help with the caregiving duties, it is ultimately the parents' responsibility to provide the majority of the support. Consistent with past research, well siblings' form of support was sporadic, inconsistent, temporal, and covered only certain aspects of care in comparison to their parental counterparts.

Relieving their parents as a form of respite care was consistently brought up by well siblings as a major aspect of the type of support they provide currently and in the future. Parents would often become too exhausted, overwhelmed, and in need of a break. Describing his family member's caregiving duties, Ethan noted that, occasionally, his mother's tasks became "super strenuous," requiring his father instead to give the "pre-bed" phone calls to Chloe to comfort her. He further mentioned, "my parents like that I phone her from time to time, the encouragement of that, so in some respect sometimes my parents need to get away for a couple of weeks, so she stays with us for I think it was a week, so that sort of thing." Similarly, Sienna explained:

My mom, she is getting more and more fed up with him, so I mean when he's at my parents place, she just calls me and says "I can't handle anymore. Can you take him, just take him get him out of here!" Like on Christmas day or Christmas eve, I was supposed to go to their place around five, but around two o'clock my dad and my brother showed up and my dad's like "Carter got kicked out, so can he stay here for a bit until I come pick you up at 5?" and I was like "yes that's fine."

In taking care of a relative with a SMI, family members' needs and wants can often be overlooked and "shadowed" in comparison to the problems their ill loved one faces. Sienna observed that, for most parents, supporting their ill loved one "takes over their entire lives." She

recalled her parent's experiences with Carter and how they became overly attached to their supportive role, which she could see from her experience in her sibling role: "I am out of the situation. I can see it from the outside, and I can see how it is unhealthy, and when he first went into Riverview, they were devastated, and I was like, you know, that this was a good thing because he is not going to be around you all the time, and you can have your own life now."

However, well siblings maintained that, when they eventually adopt the primary caregiving role, it would not become all-consuming and jeopardize their well-being and personal lives, in the same way that it has for their parents. However, they were uncertain as to how caregiving would impact their lives in the future:

I think I worry about it more for future stuff, for when my parents die. Like I said, Troy has always done his own thing and my sister, their relationship, is not always the greatest. So I think it would fall up to me and I am just trying to figure out how that would work. How that would work out in terms of me having a life (Jen).

In the future I have to think about my own sister's closeness to my family and that basically is 50 percent of my parent's life is her, so when they're gone, then how is that going to change my role in terms of not just financial stuff, but does my partner want to have my sister come and visit more often. Not in a bad way, but we are going to have to deal with it (Ethan).

I think that the phone calls definitely takes up a lot of my time because he's calling all the time, and I am at work, my phone is always buzzing, so that takes up a lot of time, but I don't let it take over my life. I try to live my life.... Well that's a huge weight on my shoulders. I think when the time comes, I will deal with it. It'll be hard, but I will deal with it in a way I think is best. I've told my mom I can't be like them though. He can't be here every weekend and I'm not prepared to let that happen because I need to have a life too, right? (Sienna)

Thinking about their loved one's future care was a source of added stress. When I asked how well siblings might be involved with their ill brother or sister in the future, a couple of the well siblings had not considered the future and were surprised by the question. Living in the moment, Claire took things with Luke as they "unfold[ed]," and was defensive when discussing the future, and questioned if she should be concerned about it. As parents aged, well siblings

believed that the burden of care would ultimately pass on to them, but they felt that would still only provide specific aspects of care. They hoped that by the time the transfer of care would arise, their ill brother or sister would be somewhat independent and be able to function daily on their own accord.

Well siblings imagined how their ill sibling would be incorporated into their daily lives in the future. Moving forward with their own lives made it increasingly troublesome for well siblings to conceptualize what the future would hold and what their involvement with their ill sibling would look like. Jen stated, “Well I want to be a doctor and I want to have a family and all that stuff. I kind of worry about how...if stuff happens...I can kind of drop things and just kind of be with him. I don’t picture myself living in Canada. So that would be hard—harder to kind of be with him.” When I further asked her if Joe’s illness would impact her decision to live in Canada, she replied that it would, and that it was something that she was unselfishly willing to do for him.

Well siblings also learned to negotiate with others in their lives that were affected by the illness and arrive at some sort of common ground. They envisioned the way this would “pan out” in the years to come as well, and how the people close to them in their lives would react. In addition, in some instances they prioritized the illness to fulfill the demands of caregiving. Holden defined caregiving by putting the needs of the individual in front of their own: “I think the caregiver’s own life and sometimes prioritize their life before the person who they are helping or taking care of.” Jen prioritized the illness during her daily routine, for example, in her “free time, maybe in terms of making sure that when my mom asks me to do stuff for Joe, making sure that that gets done before I do stuff.” However, it is important to remember, as Bank and Kahn (1982) expressed, “there are abundant possibilities for siblings not adequately meeting

each other's needs" (p. 33). Well siblings should not be "too hard" on themselves if they are unable to fulfill both their own needs and those of their ill siblings.

None of the well siblings were the primary caregivers, with the exception of Tyler, who recently adopted this role because of the recent death of his mother from stomach cancer. Two months following her passing, Tyler's father formally asked him to be the "point person." The caregiver burden became too great as a result of his wife's death, the subsequent grieving, and the constant disruption and overwhelming feelings experienced from his son's tumultuous and erratic behaviour. The unpredictability of his son's behaviour and frequent drug use (i.e., smoking crack cocaine) was a stressor. Tyler adopting the role of primary caregiver was the result of the aging parent's gradual inability to provide support because of his increasing health problems.

Amy, Jen, and Troy felt that their parents would ask them to become the primary caregivers. Even if well siblings' are unwilling to be the primary caregivers in the future, it may be the only option available due to the lack of mental health services and resources, and the demographic shifts in the population. As parents, these well siblings may also take on a dual caregiving role to both the ill sibling and the ageing parents. Overall, future caregiving was a sensitive subject and none of the well siblings had a clear plan in place regarding their ill sibling's treatment and care.

## **Summary**

For the well siblings, becoming a caregiver redefined their relationship with their ill brother or sister primarily as one of dependency. They compared their affected brother's or sister's past identity with his or her present one, mourning the loss of their ill sibling's "old" self. But they also had difficulty coming to terms with the "new" self, one with a chronic illness. The

process of caregiving involved assuming responsibility for the ill sibling by attending to the ill sibling's needs and shifting their expectations of what they thought he or she was capable of. As a consequence of caregiving, the ill sibling became the focal point of family communication. Well siblings felt that they were increasingly assuming more the role of a parent. As such, they attempted to live their own lives, separate from their ill brother or sister, while balance their caregiving duties and making compromises to satisfy the needs of their affected sibling. They were also able to move 'in' and 'out' of support, providing sporadic and specialized types of care in comparison to their parents, who provided consistent and more comprehensive care. They often relieved their parents of their caregiving burden. Thinking about the future, well siblings were uncertain what their role would be, but acknowledged that they would be expected to continue assisting in their caregiving duties.

## **Chapter 8 : Discussion and Conclusion**

In this chapter, I summarize the findings in relation to the research objectives, discuss the strengths and limitations of the study, and suggest ideas for future research and recommendations for mental health practice.

### **Summary of Findings**

This study set out to explore the meanings that well siblings attribute to their experiences of caring for a brother or sister with schizophrenia. Cicirelli (1995) notes “the great bulk of sibling research in the area of disability, illness, and mental retardation has been concerned with childhood and adolescence. Much less is known about what happens to the sibling relationship during the adult years” (p. 144). This study addressed this gap in knowledge by exploring changes in the sibling relationship in adulthood after the ill sibling is diagnosed with schizophrenia. This study retrospectively examined changes in the nature of the relationship between well and ill siblings before, during, and after the diagnosis of schizophrenia. The research questions were:

- (1) How do well siblings relate to the brother or sister with schizophrenia; how has this relationship evolved before and since the onset of the illness?
- (2) How do well siblings understand the meaning of the term caregiving; what kinds of activities do they consider as caregiving activities?
- (3) In what way are well siblings currently involved in caregiving; how does this compare to the care their parents provide?

- (4) What responsibilities do well siblings feel they have in relation to the affected brother or sister; how do they believe those responsibilities will evolve as parents age?

The findings of this study reinforce past research on the sibling experience and also offer new insights. The literature generally suggests that the sibling relationship is a source of support over the life course, especially during traumatic life events (e.g., divorce, remarriage) (Cicirelli, 1995). This support has roots in the bond that siblings develop as a result of sharing common social, cultural, and genetic heritage within the family system (Nechmad et al., 2000). The well siblings in this study reported maintaining a close and caring bond with their ill siblings prior to the onset of schizophrenia. In their teenage years, the well siblings reported growing apart from the ill sibling as they developed interests outside of the family. The onset of schizophrenia altered the sibling relationship in significant ways. In the pre-diagnosis phase, well siblings were affected by the often dramatic changes that occurred in the ill sibling's personality, behaviour, and lifestyle. They reported this period of time as emotionally draining because they did not know what was wrong. After the diagnosis of schizophrenia, well siblings reported becoming more involved in providing support to their ill sibling but also felt the quality of their relationship was diminished as a result. This corroborates findings reported in several reviews of research on family caregiving and schizophrenia (Awad & Voruganti, 2008; Baronet, 1999; Brady & McCain, 2004; Loukissa, 1995; Saunders, 2003; Teschinsky, 2000). The main reason for the diminution in the quality of the relationship was the ill sibling's problematic and bizarre behaviour.

Several studies have described the impact of schizophrenia on sibling in terms of burden (e.g., Barak & Solomon, 2005; Barnable et al., 2006; Chase, 1983; Friedrich et al., 1999, 2002;

Gerace et al., 1993; Landeen et al., 1992; Lively et al., 1995, 2004; Rubenstein et al., 2002; Smith et al., 2007; Stalberg et al., 2004; Titelman & Psyk, 1991). However, few studies have addressed the evolution of the sibling relationship over the course of the illness. This study addressed this gap in knowledge, albeit retrospectively. One of the key findings of this study in this regard is how the diagnosis of schizophrenia acted as a “master status” (Goffman, 1963) and shaped the way well siblings came to view their ill brother or sister. Once the diagnosis was made, well siblings began defining their ill sibling primarily in terms of the illness. Well siblings saw their sibling in a different light and compared the past healthy self with the ill self. Another finding was that well siblings experienced a grieving process similar to what one would experience with the death of a loved one. They mourned the loss of the brother or sister they once had and struggled to come to terms with the chronic nature of the illness. This finding corroborates similar accounts of this process in other studies (see Brodoff, 1988; Brown, 1996; Stalberg et al., 2004; Stein & Wemmerus, 2001).

The well siblings also reported undergoing a role reversal—assuming more of parental role with their ill sibling. As caregivers, well siblings viewed their relationship with the ill sibling in terms of dependency, similar to a parent–child bond. This role was defined by the nature of the well siblings’ caregiving activities. Siblings who engaged in maintenance type activities (e.g., overseeing meals, finances, etc.) experienced much stronger role reversal and reported the ill brother or sister as more dependent upon them. Role reversal was also accompanied by efforts on the part of well siblings to balance their caregiving responsibilities and meeting other obligations at work or with their own family.

Interestingly, most well siblings in this study did not see spending time with their ill sibling as a source of burden. Rather, they saw this time as a way to nurture sibling bond and

reaffirm the strength of their relationship. This finding challenges past research on family caregiving and schizophrenia which describes sibling involvement exclusively in terms of 'burden.' This finding suggests the need for a broader exploration of sibling caregiving which can capture the diversity of experiences in this population.

This study also found that sibling caregiving differed from parental caregiving. Sibling support was sporadic, inconsistent, and less comprehensive than the care parents provided. This finding is consistent with what has been reported in the literature in this regard (see Hatfield & Lefley, 2005; Smith et al., 2007). The level of support provided by the well siblings was influenced by geographical proximity, parental requests for assistance, and parental availability and capacity. These findings have also been reported in several other studies (see Hatfield & Lefley, 2005; Horwitz, 1993a, 1993b, 1994; Horwitz et al., 1996; Jewell & Stein, 2002).

Siblings in this study reported being unwilling to provide the same amount of support in the future that their parents currently provide. The siblings were for the most part unsure of what responsibilities they would have to assume in the future if their parents became too frail to continue with caregiving. They expected to provide some form of support, but hoped that it would not be as consuming as it was for their parents and believed they would have to make compromises in their own lives in order to satisfy the needs of their ill brother or sister. Discussions in this regard were lacking between well siblings and parents. This issue was a source of concern for the siblings--a finding which has been reported in other studies (see Hatfield & Lefley, 2000; Lefley & Hatfield, 1999; Smith, 2004). This finding suggests the need to further explore caregiving transitions between aging parents and well siblings.

## Strengths and Limitations

This study has several strengths. The sample represented a broad range of caregiving experiences of well siblings of people with schizophrenia. In-depth semi-structured interviews enabled an in-depth exploration of the well siblings' experiences. In addition, follow-up interviews allowed me to explore the topics that I felt were underdeveloped in the original interviews, but which were important and needed further elaboration. This research is also unique because it offers a rich, qualitative description of the evolution of the relationship between well and ill siblings from before, during, and after the diagnosis of schizophrenia, and retrospectively traces how well siblings became caregivers over the life course.

There are two main limitations to this study. The sample size is relatively small ( $n=10$ ).<sup>42</sup> While specific procedures of grounded theory were implemented to analyze the data, theoretical sampling in regards to data collection was not undertaken. This was because of the logistical concerns and restraints of the study. As a result, theoretical saturation was not achieved. This would have likely required another 20 participants, which would have expanded this project beyond what is required for a MA thesis. Finally, all participants, with the exception of one, were Caucasian, English-speaking, and primarily middle to middle upper class. Further research is needed with a more diverse sample, with well siblings from other cultural and socioeconomic backgrounds who might have different experiences caring for a brother or sister with schizophrenia.

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<sup>42</sup> However, other qualitative studies on the sibling experience and schizophrenia contain similar sample sizes. For example, Barnable and associates (2006), in a phenomenological study, sampled six well siblings of people with schizophrenia.

## **Implications for Future Research**

A major finding from this study is the inconsistent and sporadic level of support provided by well siblings in comparison to their parents. Parents have the responsibility to plan ahead for when they are unable to manage the support for people with SMI and find adequate replacements for when they are gone. It is imperative to investigate further what expectations well siblings have for the future in terms of caregiving. A future comparative study of non-caregiving and caregiving siblings may prove beneficial in better understanding the reasons behind why some provide support, others do not, and how we can get siblings more involved in the caregiving of their brother or sister. Another area of inquiry could be the ways in which well sibling caregivers balance their own lives with their supportive role and manage this juggling act. A grounded theory could be conducted to gain a better understanding of this understudied aspect of research. A focus group or series of in-depth interviews with father, mother, and sibling caregivers may also offer further insight into the family dynamics that they experience and the ways in which they perceive support for an affected relative. Future research and the findings in this study could also be extended to other groups of caregivers and forms of SMI such as bipolar disorder.

Sibling research initiatives may further focus on (1) longitudinal design; (2) homogeneity with specific inclusion criteria (i.e., isolating sibling studies to schizophrenia rather than including other mental illness); (3) broadening the concept of burden; (4) the effect of the position of siblings in the family; (5) personal relationships and second generation; and (6) the role of health providers for sibling support (Nechmad et al., 2000).

## **Recommendations for Mental Health Practice**

The experiences of the participants corroborated previous research and this underscored several crucial implications for mental health practice. Well siblings in this study were largely dissatisfied with mental health services to fulfill their caregiver needs. They also felt dismissed and underestimated by professionals, and excluded from their affected brother's or sister's treatment plan. Mental health professionals must learn to acknowledge and value the influential role well siblings have in the current and future care of their ill brother or sister, thereby accessing another source of knowledge regarding the ill relative's history and experiences. It is essential for them to view the sibling relationship as a resource to people with SMI and help siblings recognize that their involvement matters and has a positive impact. The individual with SMI should be seen by professionals as situated within the family context and influenced by these social factors.

It would be of value for mental health professionals to better integrate siblings into the decision-making process of their loved one's treatment. They should be included as active and respected members of the treatment team to offer their perspective and to be available to inform the care plan by talking with the physician and interdisciplinary team. As part of the treatment team, they should be provided regular feedback throughout their loved one's treatment, consulted in discharge planning, especially from hospitals, or given any relevant information (i.e., access to collateral information). Staff may also initiate family contact when the loved one is stable, document their involvement in his/her case record, and gather family knowledge and viewpoints in preparing his/her history. Siblings should be encouraged to attend appointments (where fitting) with their ill loved one. If siblings feel listened to and included by mental health professionals in their ill brother's or sister's treatment, they will most likely provide more

support. This inclusion of well siblings into the treatment plan will complement the existing viewpoints from professionals, contribute to a comprehensive treatment regime, and improve the overall well-being and recovery of the ill relative. A collaborative approach between professionals and family caregivers will facilitate an exchange of information and a sense of ownership and shared responsibility in the ongoing demands of care that best serve the needs of the ill relative while promoting the experiences of families. At the structural level, there must also be a commitment by management to shift from the current models of practice to a more collaborative approach that emphasizes family involvement.

Mental health professionals would benefit from mandatory educating or training for working with families. Staff would be taught in individualized and group sessions about various topics, including building relationships with families, effective communication skills, conflict resolution, and information sharing regarding confidentiality issues. Additional training will ensure that professionals have the necessary skills and competencies to work effectively with family caregivers to cultivate a constructive environment conducive to the promotion of well-being and recovery for the individual with SMI. It is imperative that professionals learn to create a therapeutic setting that does not place blame on the family or undermine their integral position in the recovery process.

The importance of a broad spectrum of psychosocial interventions to assist sibling caregivers and their ill brother or sister must be stressed. There is a growing need to create coordinated support services for families that are accessible to caregivers in the community, adequately funded, and properly promoted by health service providers. Family-oriented support services that take into a greater account the role of siblings in caregiving should be developed. While sibling-oriented services have emerged in the United States, there is a need for such

services in Canada (Landeem et al., 1992). For instance, the National Sibling Network, which is a large network that organizes self-help support groups for siblings, has been established in the United States under NAMI. These psychosocial interventions are similar to well-established family-oriented services. Mental health professionals should also encourage siblings to seek social support from family, friends, and organizations such as NAMI, to better cope with the demands of the illness. Family-oriented services include psycho-education, family education, family consultation, and family support and advocacy groups (Marsh & Johnson, 1997; Solomon, 2000). The services that are developed to address families' caregiving concerns could be adapted to specifically suit their needs.

Support groups are an increasingly popular, cost-effective, and widespread resource for family caregivers of people with SMI whose needs are often unmet by private and public health services (Heller et al., 1997). Sibling support groups should emphasize the distribution and acquisition of information regarding schizophrenia. In addition, these groups must provide opportunities for siblings to interact and share their individual experiences through interpersonal learning in a supportive and communicative setting. This approach may seem geared toward siblings who do not have a substantial caregiving role, but seek to learn more about the illness and are worried about over involvement with mental health professionals.

Siblings who suffer from emotional problems or are unable to cope adequately may need to seek out intensive psychotherapy sessions with a mental health professional such as a psychologist. At these sessions, siblings could discuss the meaning of their experiences and the impact of schizophrenia on their relationships, well-being, and so forth. Siblings should be able to access affordable or free counselling to help them work through typical feelings such as anger, guilt or resentment. Counselling would provide siblings the opportunity to discuss their

unresolved issues, address their unique concerns, and validate their experiences. Access to counselling should also happen in a timely manner so that family members can obtain assistance efficiently. Grief counselling would help siblings mourn the loss of their 'past' brother's or sister's healthy self, and move them toward acceptance of the illness.

Another suggestion is to include siblings in family therapy. For example, Harris (1988 as cited in Denberg, 1996) included siblings in family therapy sessions in an effort to weaken strict family roles and in turn to have the siblings' needs acknowledged. It would also allow the family to set realistic expectations and guidelines regarding their roles in care, and discuss how they can maintain a positive family experience to benefit all parties involved. Including siblings in family therapy may be problematic and may not be as beneficial as other sibling-oriented services because of the distinct needs and concerns of siblings, which differ from those of parents and relatives. Including them, however, may be therapeutic in dealing with family issues that relate to the illness and may help solve issues concerning family communication and interaction. Some sibling support groups could emphasize a more expressive focus as well. Overall, sibling support in conjunction with treatment will lead to better outcomes for the individual with SMI, as well as the family, and reduce the use of mental health services.

A central finding of this study consistent with past research was that siblings provided intermittent, temporary, and certain aspects of care in relation to their parent's support. Some siblings mentioned that their other well siblings did not currently provide any support to their ill relative. Sibling-oriented support services should be directed primarily at developing resilience and enhancing constructive coping and adaptation strategies that avoid excessive conflict and anger, which will reduce siblings' stress and caregiver burden. In addition, support services would be aimed at helping them manage crises, strengthening communication skills, and

improving their problem-solving abilities in regard to how they deal with schizophrenia.

Minimizing the negative effects of the illness will increase their likelihood of current or future caregiving.

Siblings had difficulty trying to balance their own lives with their caregiving duties. An approach should be sought that “seeks to help siblings and other caregivers achieve balance and control in their lives to enhance the capacity to choose alternatives on the basis of practicality balanced with the acceptability of their consequences” (Solomon, 2000, p. 100). This approach would focus on self-help groups and seminars to ‘work through’ the emotional burden related to schizophrenia and caregiving, altering the perception of the siblings’ sense of self, and relationship to the ill brother or sister. Life skills training will also help equip siblings to better manage and fulfill their own wants with their ill brother’s or sister’s needs that arise from the demands of caregiving.

Community programs should also provide family psycho-education on SMI. Families need to receive practical information on the structure and availability of mental health services, such as where to access counselling. Adequate information that is clear and precise on not only the biological but also the social aspects of SMI needs to be made readily available at primary and tertiary care facilities to family members and the affected relative suffering from psychosis. It would be especially useful to have more information/brochures available at the ED or inpatient units, when the family and ill member have their initial contact with the mental health system. During immediate crises, it is imperative that professionals provide straightforward answers and useful advice to informal caregivers, who are usually confused and traumatized from experiencing the illness. Obtaining information on SMI is an important step for family members to begin to come to terms with the illness.

Siblings in this study often attempted to avoid mental health services because of the mixed messages, negative interaction, and poor resources from professionals. It is surprising that mental health professionals arguably possess the most knowledge regarding schizophrenia and would be the most helpful, yet are reported as one of the least available or utilized resources (Landeem et al., 1992). Siblings should not have to depend on seeking information from other sources in the community, such as from support groups and books written by lay people. Given the desire of informal caregivers for consistent, reliable, and accessible information from professionals, information on schizophrenia, such as prognosis, and its treatment should be incorporated into the ill relative's care plan. This will provide family caregivers with a foundation of knowledge concerning SMI that they can apply to their day-to-day experiences supporting their ill loved one.

Siblings would greatly benefit from an increase in the availability of respite care services by mental health providers. This is crucial if siblings become caregivers to both ill siblings and ailing parents. An increase in respite services would reduce some of the day-to-day burden sibling caregivers experience and provide them needed rest and relief from support. Distributing the share of responsibility among respite services and caregivers will help alleviate tension that builds up in the home and will provide siblings with some independence. These services would be designed similar to the non-profit organization PLAN to assist with the long-term support and care planning of the individual with schizophrenia. Sibling caregivers will require an opportunity to attend to their own personal needs and fulfill the competing demands of their families and obligations. This will improve the overall well-being of the family system. Consequently, community programs such as housing facilities, need to be increased. Increasing these services will help relieve some of the ongoing burden of support experienced by informal caregivers

while substituting for the comprehensive support siblings' parents previously provided, as their caregiving abilities decline with age. In addition, there must be advocacy for more services for the ill person so the burden will not rest solely on sibling caregivers in the future. It is the duty of mental health professionals to orientate new primary caregivers (especially siblings) to available respite services, inform them if changes to respite services occur, and encourage them to utilize this form of support.

Informal and formal caregivers should plan the future care of individuals with schizophrenia well ahead of time, before the transfer of care takes place from parents to siblings. Yet, most informal caregivers operate on a 'one day at a time' philosophy. Since siblings are expected to take on a greater share of this care, siblings need to be incorporated in the long-term care planning for their ill loved one. They will assist in considering all the viable and alternative sources of care available. There needs to be open dialogue and a clear resolution with respect to future plans among the caregivers and the individual with schizophrenia. At these collaborative meetings, topics could focus on the concerns for the future of their ill brother or sister, future living arrangements of the ill relative, reasonable expectations of future care for the person with SMI and for well siblings, or legal matters (especially siblings' rights to obtain information once their parents pass away). Preparation, through counselling, for the death of a parent may alleviate some of the stress and apprehension that siblings will experience as their parent's age and eventually pass away.<sup>43</sup> It would also be useful if siblings were provided assistance to help them transition to full-time caregiving. By equipping well siblings with the social skills and interventions necessary, they will most likely be more capable and willing to provide care

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<sup>43</sup> For other suggestions on how mental health professionals can improve family support and involvement for people with schizophrenia, see the *Family support and involvement plan for the adult mental health program in Vancouver* (VMHS, 2004).

presently and to anticipate earlier in their lives their future role caregiving. This will hopefully allow siblings to be able to properly balance their own lives with their duties supporting their ill loved one without becoming as overwhelmed or exhausted like their parental caregivers.

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## Appendix A: Recruitment Poster



University  
of Victoria

Department of Sociology  
University of Victoria

Do you have a brother or sister living with schizophrenia?

If so, you are invited to participate in a study on the experiences of well-siblings of people with schizophrenia.

Hello. My name is Chris Dodge. I am an M.A. student in the Department of Sociology at the University of Victoria. I am interested in learning about the experiences and concerns of adult siblings with a brother or sister diagnosed with schizophrenia. The findings from the study will help better understand the role of well siblings in relation to those affected by schizophrenia and possibly help in the development of sibling-oriented support services.

Participation in the study consists of an interview at a time and location convenient to you. The interview will be no more than one hour in duration. I am also asking people to volunteer for a brief follow up interview of about 30 minutes in duration.

Involvement in this study is entirely voluntary and all information will be kept strictly confidential. You will not be identified by name in any of the reports or academic publications coming out of this study. Any information that does identify you or your family will be omitted or changed in the final reports. Be advised that declining participation in this study will not affect the current or future services you receive through the list serve. You may also wish to discuss your potential participation in this study with your brother or sister or other family members. This study is being conducted to fulfill the requirements for my Masters of Arts in Sociology.

If you want further information about the study or want to participate, please contact Chris Dodge by phone at (778) 997-7142 or by email at: [cdodge@uvic.ca](mailto:cdodge@uvic.ca) or my supervisor Dr. André Smith at [apsmith@uvic.ca](mailto:apsmith@uvic.ca) or (250) 721-7583.

**Appendix B: Letter of Support**

To: The Human Research Ethics Board of the University of Victoria

Please know that I have reviewed Chris Dodge's research project on people with a sibling who suffers from schizophrenia. I have also reviewed the recruitment procedures. I strongly support the purpose of this project and the methods that are being used. I believe that Chris' work draws attention to an overlooked segment of the community and can, in the future, be extremely useful in educating families and service providers about the needs of siblings.

Sincerely,  
\*\*\*\*\* \*\*\*\*\*

## Appendix C: Interview Guide – Part 1

Thank you for participating in this study. I am interested in understanding your experiences with having a brother or sister diagnosed with schizophrenia. Feel free to openly share with me anything that comes to mind and that you feel comfortable discussing.

- 1 Could you describe the current living arrangements for your family?
  - 1.1 Parents
  - 1.1 Sibling with schizophrenia
  - 1.2 Other siblings
  - 1.3 Yourself
  
- 2 Who provides support to your brother/sister among your family?
  - 2.1 Who provides most of the care? How come?
  - 2.2 Who is less involved in providing care? How come?
  
- 3 What is involved in providing support to your brother or sister with schizophrenia?
  - 3.1 Type of activities
  - 3.2 Responsibilities
  
- 4 How would you define the term caregiving?
  - 4.1 What do you think it involves?
  - 4.2 Who would you consider a caregiver?

I would like to ask you questions concerning your experiences as a sibling of someone with schizophrenia

- 5 What is your brother/sister like before the onset of the illness?
  - 5.1 Personality
  - 5.2 Relationships with parents, siblings and friends
  - 5.3 Past involvement in activities, e.g., schooling, sports
  
- 6 What is your brother/sister like now?
  - 6.1 Personality
  - 6.2 Relationships with parents, siblings and friends
  - 6.3 Current activities
  
- 7 When did find out that your brother/sister had schizophrenia?
  - 7.1 How did you feel?
  - 7.2 What were your thoughts?
  
- 8 How were you involved with your brother or sister prior to the schizophrenia?
  - 8.1 Activities before the illness?
  - 8.2 Your relationship before the illness?
  - 8.3 Time spent together before the illness?
  
- 9 How are you currently involved with your brother or sister with schizophrenia?
  - 9.1 Activities?
  - 9.2 Your relationship?

- 9.3 Time spent together?
- 10 How has your role changed in the family since your brother/sister's condition?
- 10.1 As a brother/sister to your sibling with schizophrenia?
  - 10.2 As a son/daughter to your parents?
  - 10.3 As a brother/sister to other siblings?
- 11 How has your brother/sister's illness impacted your life?
- 11.1 Relationships with your family members? Friends? Peers? Others?
  - 11.2 What about your activities/free time? Work? Responsibilities?  
How has the condition affected your well-being
- 12 What are the concerns you have about brother/sister with schizophrenia?
- 12.1 Concerns about their future?
  - 12.2 Concerns about your future?
- 13 How might you be involved with your brother/sister in the future?
- 13.1 Activities?
  - 13.2 Responsibilities?
- 14 How would you describe your experience with the mental health system?
- 15 Any other thoughts or feelings you would like to share?

Thank you for your time and participation in this study.

### Appendix D: Interview Guide – Part 2

I would now like to ask you some demographic questions that will help me better characterize the people who participate in this study

Date of interview:	
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#### Well-sibling

Age	
Gender	
Current occupation or activity, e.g., student	
Occupation or activity when sibling was diagnosed	
Education	
Residence, e.g., apartment by self, with parents, with partner	
Marital or relationship status	
Age at the time of sibling diagnosis	
Age of father (or deceased)	
Age of mother (or deceased)	

#### Sibling with schizophrenia

Age	
Gender	
Current occupation or activity, e.g., student	
Education	
Residence, e.g., group home, apartment by self, with parents	
Marital or Relationship Status	
Estimated sibling age at the onset of schizophrenia	

Sibling age when diagnosed		
Other well-siblings' age and gender		

## Appendix E: Consent Form



University  
of Victoria

### *Participant Consent Form*

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#### *Caregiving and schizophrenia: The well siblings' perspective*

**Principal Investigator:** Christopher Dodge, M.A. candidate  
Department of Sociology,  
University of Victoria  
(778) 997-7142 or by email at: cdodge@uvic.ca.

You are invited to participate in a study entitled '*Caregiving and schizophrenia: The well siblings' perspective.*' This study is conducted under the supervision of Dr. André Smith as a requirement for the Master of Arts in Sociology at the University of Victoria.

#### **Purpose**

This study explores the experiences of siblings who have a brother or sister diagnosed with schizophrenia. More specifically, the study aims to investigate siblings' relationships with their ill brother or sister; their experiences and understanding of caregiving; and their concerns with future caregiving responsibilities.

This study is important because siblings of people with schizophrenia have unique experiences that are not well-documented in the research literature. The information you provide will help mental health professionals better understand sibling involvement in schizophrenia and possibly contribute to the development of sibling-oriented support services.

#### **Participation**

You are being asked to participate in this study because you are a sibling, 19 years of age or older, who has at least monthly contact with a brother or sister diagnosed with schizophrenia. You will be interviewed for approximately one hour. You will also be asked to take part in a 30-minute follow up interview to verify the accuracy of the findings derived from your interview. A summary of the findings will be available to you, if you choose to request one.

Your participation in this study is entirely voluntary and no compensation for your participation is offered. All information will be kept confidential. No information will be released which will personally identify you. The transcripts, interview notes and electronic documents will be kept in a locked filing cabinet. If you decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw, your data will be deleted from the study and your records will be destroyed.

### **Confidentiality**

Your identity will be kept strictly confidential in a number of ways. Only the Principal Investigator and his supervisor will have access to notes, transcripts and interview recordings. All recordings, transcripts and other documents will be stored in a locked filing cabinet and transcripts will not contain respondents' identifying information. All documents associated with your interview will be identified only by code number. The key to these numbers will be kept only by the principal investigator and will not be publicly released under any circumstances. You will never be identified by name in any reports or publications derived from the completed study. Only pseudonyms will be used in the reports and other materials that derived from the study. The transcripts, interview notes and electronic documents will be kept for a period of 7 years, after which time they will be destroyed. The results of this study will be shared with others in the following ways: a summary of the findings given to participants upon request; published articles in scholarly journals or newsletters; thesis; presentations at scholarly meetings and family support groups and events sponsored by BC Schizophrenia Society.

You may wish to discuss your participation with your brother or sister and other family members. Many family members of people with schizophrenia in the Vancouver community know each other through common membership of various support groups and by attending similar functions and events relating to mental illness. There is thus a possibility that certain aspects of your experiences could be identified by family members when they read the report or attend a presentation of the findings. Every effort will be made to disguise circumstances that could identify you, your sibling, or your family, in the reports and publications coming out of this study. However, it is still possible that you, your sibling, or your family, may be identified by individuals who are familiar with the particular circumstances surrounding your involvement with a brother or sister with schizophrenia.

### **Remuneration**

Your participation in this interview is entirely voluntary and no payment for your participation is offered.

### **Your Rights**

A possible risk is that you may experience some emotional discomfort when being interviewed about your experiences. If you become distressed, feel free to request a break to compose yourself. Your participation is entirely voluntary and you are free to refuse to answer any question or end the interview at any time. If you have any questions or want further information about the study, please contact Christopher Dodge at (778) 997-7142 or email: [cdodge@uvic.ca](mailto:cdodge@uvic.ca) or Dr. André Smith at [apsmith@uvic.ca](mailto:apsmith@uvic.ca) or (250) 721-7583. In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or [ethics@uvic.ca](mailto:ethics@uvic.ca)).

Your signature below indicates that you understand the above conditions of participation in this study, have had the opportunity to have your questions answered by the Principal Investigator, and have received a copy of this consent form for your own records.

<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
<i>Name of Researcher</i>	<i>Signature</i>	<i>Date</i>

**Follow-up interview and recording**

- I consent to participate in a follow-up interview of approximately 30 minutes in length.
- I consent to have this interview audio recorded.

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### ***List of Available Support Services***

#### ***Caregiving and schizophrenia: The well siblings' perspective***

Here is a list of registered psychologists and counsellors available in the Greater Vancouver Area that has been referred to me by the British Columbia Psychological Association through their website and telephone referral service.

Feel Free to contact them, if you wish to seek support from other individuals or services from their website at [www.psychologists.bc.ca](http://www.psychologists.bc.ca) and/or contact them at (604) 730-0522 or toll free at 1-800-730-0522.

The counsellors listed provide general support, psychotherapy, and counselling services and specialize in the areas of grief and loss; family relationships and conflicts; stress and anxiety related issues; and adjustment to chronic pain, illness and/or disability.

Counsellors are available weekdays, evenings, and weekends through appointment. Payment and fees vary by counsellor and are usually discussed during the initial interview with the counsellor. You may contact the counsellors to discuss these issues further.

<b>Name</b>	<b>Address</b>	<b>Phone</b>
Ms. Susan Rungta	Suite 206 4545 West 10th Vancouver	ph: 604 222-1116
Dr. Donna Paproski	#325 - 2184 West Broadway Vancouver	ph: 604 619-0849
Dr. Trish Crawford	#204 - 2211 West 4th Ave. Vancouver	ph: 604 737-2567
Dr. Anne Dietrich	#209-6700 No. 3 Road Richmond #200-1892 W. Broadway Vancouver <a href="http://www.annedietrich.ca/">http://www.annedietrich.ca/</a>	ph: 604 889-3787