Mental illness in the family: A qualitative investigation of the sibling experience

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Abstract (English):

Objectives: Research on the family burden of mental illness has traditionally centered on parents as caregivers and the social and economic impacts on families more broadly, largely neglecting the sibling experience. Three primary objectives were established for this thesis: to explore and describe the experiences of well siblings with a sibling with anxiety and/or depression; to identify key messages for other young adults and for families in similar situations; and to develop key messages and recommendations for healthcare professionals to improve access to care and support for this group. A team between St. Mary's Hospital Centre and McGill University has been established to create a Canadian version of the award winning web site (www.healthtalkonline.org) that presents lived experiences of health and illness. A module on mental health is in development and the exploratory work for this graduate thesis in family medicine aims to contribute insights to support research and engagement with young adults for future modules in this larger initiative.

Methods: The methods adopted for this thesis included two components: a review of available literature; and, primary data collection of individual self-reported experiences of well siblings collected through three focus groups. The review of literature was conducted using major databases [PubMed, MEDLINE, PsycINFO, with articles restricted 1985-present]. Focus groups utilized a qualitative narrative approach to explore the well sibling experience, and their specific needs for information and support. Analysis of the focus group data was conducted using thematic narrative analysis and iterative review.

Results: A review of the relevant literature indicates that there is limited evidence, specifically firsthand knowledge from siblings themselves about their experiences and relevant supports. A total of 17 young adults who had a sibling suffering from anxiety and/or depression participated in one of three focus groups. The analysis of their reported experiences identified four primary themes: impact of illness on family dynamics; role of the well sibling; positive impact on well sibling; and negative impact on well sibling. In terms of implications for the support of well siblings, their experiences and responses were grouped under two primary themes: information, support and professional services; and advice to others.

Conclusions: In the context of a small exploratory study, well siblings offered key insights regarding the challenges and benefits related to their experience of living with a mentally ill sibling. Important implications and messages emerged for professionals and family members to improve the care and support provided for well siblings. Given that the available evidence about the experiences of siblings in families with mental health problems is limited, the results from this thesis contribute to the existing knowledge base and highlight areas for future research.

Abstract (French):

Objectifs: Dans le domaine de la maladie mentale, la recherche sur le fardeau familial est principalement concentrée sur les responsabilités parentales et les conséquences sociales et économiques des familles des individus avec un trouble mental; elle néglige souvent les expériences vécues par les frères et sœurs des personnes affectées. Cette thèse est organisée autour de trois objectifs: explorer le vécu et l'expérience de la fratrie sans symptômes de maladie mentale (ce groupe sera désigné par la suite comme "la fratrie sans-symptômes") avec des frères/sœurs vivant avec l'anxiété et/ou la dépression; identifier les principaux enjeux pour informer d'autres jeunes adultes et leurs familles qui sont dans les mêmes situations pour qu'ils puissent en bénéficier; et développer des recommandations pour les professionnels de la santé afin d'améliorer l'accès aux soins et le soutien moral pour la fratrie des individus avec un trouble mental. Une équipe joignant les forces du Centre hospitalier de St-Mary's et de l'Université McGill a été formée afin de créer une version canadienne du site web (www.healthtalkonline.org) qui présente des expériences vécues de maladie et de santé. Un module axé sur la santé mentale est en cours de développement sur ce site. À cet effet, le travail exploratoire de ce mémoire en médecine familiale vise à étudier d'autres facteurs qui puissent contribuer vers la création d'autres modules en santé mentale, pour jeunes adultes, et ainsi renforce et supporte cette initiative canadienne.

Méthodologie: Une recension de la littérature scientifique et une collecte de données primaires d'expériences individuelles de fratrie sans-symptômes (récoltée parmi trois groupes de discussion) sont les deux composantes méthodologiques de cette étude. La recension de littérature a été réalisée auprès des bases de données PubMed, MEDLINE, PsycINFO, incluant seulement les articles depuis 1985. L'approche qualitative de groupes de discussion a été choisie car la narration des membres de ces groupes permet d'explorer leurs expériences et leurs besoins d'information ou de soutien. L'analyse des groupes de discussion a été effectuée suivant une analyse thématique de la narration et d'une critique itérative.

Résultats: La recension des écrits indique qu'il y a peu d'études sur le vécu de fratrie sans-symptômes avec un frère ou une sœur avec une maladie mentale notamment sur leurs vécus et leurs expériences directes. En tout, dix-sept adultes ayant des frères/sœurs vivant avec l'anxiété et/ou la dépression ont participé aux groupes de discussion. L'analyse des groupes de discussion a permis d'identifier quatre thèmes principaux: Les conséquences de la maladie sur les relations familiales, le rôle de la fratrie sans-symptômes, les conséquences positives sur la fratrie sans-symptômes, ainsi que les conséquences négatives. Sur le plan du soutien et de l'aide pour cette cohorte, deux thèmes principaux ont été identifiés: information, soutien, et services professionnels; et conseils à autrui.

Conclusion: Dans le cadre de cette étude exploratoire, les participants ont contribué des informations importantes concernant les difficultés et les avantages liés à leurs vécus avec leurs frères/sœurs avec un trouble mental. Des messages et des conseils pertinents ont été identifiés pour informer les professionnels et les membres de la famille des enjeux dans l'amélioration des soins ainsi que le soutien fourni à la fratrie des individus vivant avec la maladie mentale. Étant donné le peu de recherche disponible au sujet de ce groupe, les résultats de ce mémoire ajoutent aux connaissances existantes et suggèrent des pistes pour d'autres études dans le futur.

Preface:

This thesis represents the culmination of work and learning that has taken place over a period of 20 months at both McGill University and St. Mary's Hospital in Montreal, Quebec. The idea for this research project was a collaborative effort between the author (MSc Candidate), and her thesis supervisor (Dr. Susan Law). Focus groups were organized and moderated by the author, with the assistance of Dr. Susan Law and Dr. Ellen Rosenberg. Dr. Lindsay Duncan and Celine Bailey provided administrative assistance. Sabrina Ostrowski and Marc Bruyère provided assistance with the translation of the Abstract. This research project was funded by a St. Mary's Research Center Masters Student Award in MSc Year 1, and an Anton and Demetra Karigiannis Trust Award in MSc Year 2.

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My thesis committee members also played a crucial role in the preparation and execution of my thesis. I would like to thank Dr. Ellen Rosenberg, Dr. Nathalie Dinh, and Dr. Alessandra Miklavcic for their expert guidance. Reviewing a thesis is an exceptionally time-consuming task, and I am truly grateful for the thoughtful comments I received from my committee. I would also like to thank the St. Mary's staff for their support throughout this process. Specifically, I would like to express my gratitude to Ilja Ormel and Christian Dabrowski, for their counsel, and continual encouragement.

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I could not write this acknowledgements section without recognizing my amazing family. 'Thank you' really doesn't even begin to come close to acknowledging the continual support and reassurance they have given me. I appreciate the many late nights you have spent reading my thesis and your continual belief in my abilities when at times my own confidence faltered. Last but not least, I would like to thank my biggest supporter for his overwhelming encouragement and constant support. Thank you for always believing and trusting in me and for always pushing me to achieve more than I think I am capable of.

Introduction:

This investigation is about the effects on a healthy young adult of having a sibling with depression and/or anxiety. The focus is on personal effects on the well sibling, as well as effects on the sibling relationship and family dynamics. A mental health condition in the context of this analysis is based on the healthy individual's perception that their sibling has anxiety and/or depression with a duration of six months or longer, which is relatively stable or shows a slow progression (Barlow & Ellard, 2006). The Diagnostic and Statistical Manual of Mental Disorders has defined the category known as *sibling relationship problem* as "a pattern of interaction among siblings that is associated with clinically significant impairment in individual or family functioning or the development of symptoms in one or more of the siblings" (Schuntermann, 2007). Given the definition of this category, clinicians have recently become more interested in the effect that a chronically ill sibling can have on the family unit, and are advocating for family-based intervention for the patient so that the needs of the ill sibling do not overshadow those of other family members, especially well siblings.

Research into the family effects or consequences of mental illness in a child have typically focused on the burden for parents as caregivers. Sibling experiences have not been well documented, and secondary caregivers are often undervalued and neglected in research settings (Schuntermann, 2007). Although siblings may take on the role of primary caregiver if their parents are unavailable, the sibling experience is likely different from that of their parents. Siblings' contributions as caregivers in providing support within families may be recognized by families, by their social networks and healthcare professionals, however their personal accounts of those experiences have not been well documented (Sin, Moone, & Harris, 2008). Furthermore, for well siblings who do not take on a role as caregiver, primary or otherwise, there is very little information regarding their experience of living with a mentally ill sibling. Thus, with little evidence regarding their lived experiences, and/or effective interventions for siblings such as support groups or educational resources, healthcare professionals are not well equipped to adequately address the needs of the well sibling in the context of the family burden of chronic mental health impairments.

Definitions:

A few key definitions are provided here relevant to an understanding of the context of the well sibling experience and the research conducted for this thesis. In this study, healthy young adults were invited to share their experiences of living with siblings who have anxiety and/or depression. These conditions are outlined below, although it is important to note that participants self-reported their sibling's conditions (we did not rely on formal diagnoses as a condition of participation) as it is the well siblings' perceptions that are the subject for exploration in this thesis.

Anxiety:

Health Canada states that anxiety disorders are the most common of all mental health problems and estimates that one in ten Canadians is affected. Anxiety is a common emotion experienced by all people, but those with anxiety disorders have long periods of intense feelings of fear or distress that are out of proportion to real life events (Health Canada, 2009b).

Depression:

Although most people have periods of unhappiness in their lives, depression is a clinical term used to describe a time period that lasts more than two months in which a person feels worthless and hopeless (Health Canada, 2009a). Health Canada estimates that 11% of men and 16% of women in Canada will experience major depression in the course of their lifetimes (Health Canada, 2009a).

Family:

The definition of family is challenging given that it has several meanings that may be shaped by social, cultural and individual contexts. In this thesis, I recognize that family is a broad term defined by the Oxford Dictionary as a group consisting of two parents and their children living together as a unit, or a group of people related by blood or marriage. We have chosen to use a sociological definition of family as many of the sources examining family in the literature review come from a sociological background: family structures continue to change, but today a family may be populated by step siblings and parents, by same-sex parents, by children and parents, by other relatives and increasingly, by couples alone (Vanier Institute of the Family, 2010).

For the purposes of this study, a broad notion of family was adopted without restriction to explore family dynamics of the participants in the focus groups, as it was the experience of living with a mentally ill sibling that was of more importance than the specific type of familial relationship between siblings.

Thesis Objectives

This thesis is a qualitative narrative descriptive study of the experiences of healthy young adults who have a sibling suffering from anxiety and/or depression. This thesis has three primary objectives. The first is to explore and describe the experiences of young adult well siblings who have a sibling with anxiety and/or depression. The second objective is to identify key messages for families with mentally ill siblings, through advice given by well sibling participants. The third and final objective is to develop key messages and recommendations for healthcare professionals for improving access to support from health and social services for this group. Results of the second and third objectives are to be posted on the health experiences website hosted at St. Mary’s Hospital, Montreal, Quebec.

Literature Review:

With these objectives in consideration, this literature review will present what is known about (1) healthy family dynamics, including sibling relationships; (2) the implications of mental illness on the family unit as a whole; (3) the impact of mental illness specifically on siblings; and (4) current evidence about effective care for familial mental illness.

Healthy Family Dynamics

It is exceptionally important to understand the attributes of healthy family dynamics in order to explore how relationships within families deteriorate in the presence of chronic mental illness. Researchers agree that there is no single set of attributes that constitute the perfect healthy family. Rather, relationships within a family interact to determine the health of that family. Family health occurs along a continuum, with optimal families deviant from the norm at one end of the scale, and severely dysfunctional families at the opposite end of a scale of competence (Beavers, 1982). Glaser et al. (1993) agree with this continuum theory, stating that family environments in functional, distressed and abusive families are consistent with a continuum of dysfunction, with functional families exhibiting minimal dysfunction. Strong or adaptive families are considered those who are identified by themselves or others to be successful (Krysan, Moore, & Zill, 1990). It is important to examine family relationships and dynamics before looking specifically at sibling relationships, as it is the interdependency of the entire family system and each of its members which impacts human development and growth (Glaser, Sayger, & Horne, 1993). Specifically, the psychological and social functioning of each individual has its roots in family experiences (Beavers, 1982). Home environments have also been shown to shape children's cognitive and socioemotional development, further strengthening the importance of healthy family dynamics (Menaghan & Parcel, 1991). Interestingly, parents across different ethnic groups generally agree on some of the key traits of healthy families, suggesting that some traits may be universal among successful families from varying backgrounds (Krysan et al., 1990).

Most of the research on successful families to date has focused on Caucasian middle-class families (Parke, 2000). Although families may agree upon some of the core traits of the successful family irrespective of their cultural background, family values and interactions between members vary greatly by culture. Families of minority cultures do have some values, experiences and strategies in common. These families may face invisibility, negative stereotypes, and aspirations of the majority culture (Julian, McKenry, & McKelvey, 1994). Minority families also use adaptive strategies such as parenting through extended family members, role flexibility and collectivism versus individualism to ensure the success of their family (Julian et al., 1994). They often use these strategies in combination with many of the successful parenting styles described by Caucasian families to pass on the positive values and behaviours of their unique cultural groups (Parke, 2000). These successful parenting styles that have emerged from studies of Caucasian families will now be elaborated upon.

Krysan et al. (1990) indicate that effective communication skills are one of the most frequently mentioned characteristics of healthy families. In optimal families, each member takes responsibility for his/her own thoughts and is open to communication from others. Optimal families respect the different views of reality expressed by its members, and they show a striking absence of blame or personal attack (Beavers, 1982). Family communication, such as effectively sending and receiving messages related to problem solving has been identified as a factor that promotes resilience in families (Drotar, 1997). A positive family environment which exhibits consistent discipline, and effective communication, particularly communication of family values is seen to be a major protective factor against youth engagement in delinquent or unhealthy behaviours (Kumpfer & Alvarado, 2003). Clear communication of roles within the family is also essential for family functioning. Researchers agree that clear role definition is an important characteristic of healthy family functioning and is essential for a family's ability to cope with changing situations. With a clear, yet flexible communication of family roles, family members are aware of their responsibilities, allowing them to conduct their roles effectively in the face of crises or problems (Krysan et al., 1990). Furthermore, clear communication skills and honesty are important values found in optimal families. Optimal family members recognize that hostility in one person promotes deception in another and that deception in turn promotes hostility (Glaser et al., 1993). By recognizing this cyclical pattern, optimal families stress the importance of honesty and open lines of communication to prevent deception and hostility. Finally, positive discipline methods and communication of healthy family values and expectations are among known major protective family factors which improve adolescent health behaviours (Kumpfer & Alvarado, 2003).

Social support received from parents is key in healthy families. These close, supportive relationships serve as a secure foundation for young adults' navigation of the external world. With this support, young people have more security and confidence to meet challenges in other life domains, such as negative peer influences, or academic challenges (Crosnoe & Elder, 2004). The number of supportive relationships available to children also has a positive impact on their well-being. Other nurturing adults who are readily available to children provide potential help to parents with childrearing duties and expose children to a greater range of adult caregivers, thus improving their outcomes (Menaghan & Parcel, 1991). Studies also show that the number of children in a family can impact the level of support and resources that parents are able to offer to each individual child. Families with fewer children are associated with more effective home environments (Menaghan & Parcel, 1991). In a review of studies that examined children's psychological adjustment, researchers found that family cohesion, a measure of family functioning that reflects supportive relationships, predicted far fewer behavioral problems and more competent psychological functioning in children (Drotar, 1997). Research has also found a link between the level of social support a family offers and mental and physical illness. In times of psychological need, supportive relationships can provide emotional support, guidance and tangible assistance. In fact, research has demonstrated an inverse relationship between the level of social support and indices of mental and physical illness (Holahan & Moos, 1985).

Family resources can also affect the health of a family, with increased resources fostering better family relations. More socioeconomically advantaged families are able to provide material and educational advantages to their children, which are reflected in improved cognitive skills and psychosocial resources in these children (Menaghan & Parcel, 1991). In congruence with this idea, Menaghan and Parcel (1991) also found that older mothers and those with more years of schooling were able to provide stronger home environments for their children due to their educational, and experiential resources. Families also benefit from social resources. Successful families are considered those that are not isolated, and are instead connected to the wider society. As a result of this connection, these families have external resources available to them which are essential for effective coping skills (Krysan et al., 1990).

Families who participate in family traditions or rituals are seen as highly successful. Family rituals are a reliable index of family integration, and allow for increased communication, encouraging smoothness of operation, and reduced tension and conflict. Rituals also foster family cooperation and collaboration, further strengthening relationships within families (H. I. McCubbin & McCubbin, 1988). The most commonly listed family rituals are birthdays, formal holidays, and Sunday activities such as the "Sunday Dinner" (Fiese et al., 2002). Family routines are an indication of a family's organizational skills and are important for the health and well-being of its members (Fiese et al., 2002). Interestingly, maintaining regular routines and rituals may actually protect against the family stress of divorce and remarriage. Research shows that maintaining regular routines in divorced and remarried families fosters better outcomes in children, by providing them with a sense of security and stability of family life (Fiese et al., 2002). It is also likely that families who are able to maintain routines and rituals even in the face of family conflict, such as divorce, may be distinguishable by other aforementioned characteristics, such as lower levels of conflict, or exceptional communication skills, which can also contribute to child adjustment (Fiese et al., 2002). Religious beliefs and rituals are considered an important component of strong families. This component is not measured by frequency of attendance of religious services (such as church, temple, mosque, etc.), but rather is emphasized by the fact that strong families are guided by an underlying moral and value system shared by all members (Krysan et al., 1990). Resilient families are those who are able to create an environment of predictability and continuity through rituals and routines even in the face of change and chaos (H. I. McCubbin & McCubbin, 1988).

Families face hardships as part of the natural life cycle, but it is how families overcome these hardships and challenges that determines the health and success of the family unit. Commitment to family is an essential component for overcoming challenges. When outside pressures, such as work, threaten to remove family from a top priority, members of healthy, strong families take action and make sacrifices, if necessary, to preserve the health and well-being of the family unit (Krysan et al., 1990). Research shows that women with higher levels of self-confidence are more resilient to stressful situations, and that self-confidence actually protects against psychosomatic symptoms and depression breakdowns (Holahan & Moos, 1985). Interestingly, men and women are seen to handle stress differently. Stress resistance in men is characterized by a higher amount of self-confidence, whereas for women it involves an increased number of supportive relationships (Holahan & Moos, 1985). This suggests that men deal with stress by withdrawing from social situations, whereas women deal with stress by turning towards other people. Thus, healthy families will be those that foster both a supportive environment, as well as one that is encouraging and promotes self-confidence.

Most people are able to remain healthy even under high levels of stress due to a variety of adaptive life behaviours, such as coping behaviours, and resignation in the face of failure (Holahan & Moos, 1985). Families are dynamic, and must make adjustments and changes across the family life cycle. Strong families are considered those that have the ability to end up a more cohesive, more flexible and more satisfied entity as the result of effectively overcoming stress and problems (Krysan et al., 1990). Interestingly, mothers of children with health concerns have improved home environment scores, suggesting that healthy families may compensate for stress and limitations by reinforcing the home environment (Menaghan & Parcel, 1991). In families which lack supportive relationships, research has shown that resilient youth do well educationally despite distant relationships with parents, due to strong non-parental relationships with teachers or friends (Crosnoe & Elder, 2004). This indicates the importance of supportive relationships both within the family, and outside of the home.

Distressed, or unhealthy families are recognized as those families that lack some of the aforementioned attributes found in healthy families. In particular, distressed families score significantly lower than healthy families on measures of cohesion, independence, and expressiveness and significantly higher on measures of conflict and control than normal families (Glaser et al., 1993). Furthermore, psychological distress among parents affects the functioning of children, and the family as a whole. Maternal distress for example, is a predictor of psychological symptoms among children (Drotar, 1997). The probability of youth acquiring developmental problems seems to increase rapidly as risk factors such as conflict within the family, lack of parent-child supportive relationships, disorganization, and others increase in comparison with a variety of resilience factors. In distressed families, researchers suggest that a myriad of family characteristics may be dysfunctioning, and it is therefore important to consider the interrelatedness of family characteristics. Focusing on one family dynamic may not be helpful until other interaction characteristics are addressed, as a family's communication problems may point to an underlying lack of time together, or a lack of supportive relationships among family members (Krysan et al., 1990). Parent-adolescent emotional distance is also correlated with off-track behaviour, meaning that problems with family relationships can negatively affect academic functioning in children (Crosnoe & Elder, 2004). Furthermore, researchers have concluded that disturbed intrafamily relationships may play a substantial role in the development of psychological issues that college students carry with them once they leave home (Hoffman & Weiss, 1987). This indicates that problems in the family unit can persist beyond physical separation from the family and can affect the functioning of individual members, both psychologically and academically.

We know less about sibling relationships than other relationships, however, it is clear that healthy sibling relationships promote resilience (Crosnoe & Elder, 2004). Crosnoe and Elder (2004) found that siblings may not automatically turn to one another for support, but those who rely on siblings during stressful family situations are better adjusted. Like healthy families, there is no one set of characteristics that describes typical healthy sibling relationships. In a study that interviewed sixth-grade siblings, researchers found that warmth/closeness was a characteristic recognized by siblings that was manifested in a multitude of qualities such as intimacy, companionship, admiration, similarity, nurturance and affection (Furman & Buhrmester, 1985). In the same study, the most commonly mentioned positive sibling relationship qualities were companionship, admiration, prosocial behaviour, and affection (Furman & Buhrmester, 1985). In the study conducted by Furman & Buhrmester (1985) it was shown that generally siblings feel a greater sense of closeness towards same-sex siblings, and there is greater companionship towards younger siblings than older ones. Furthermore, the age difference between siblings seems to have a significant effect on the quality of the sibling relationship. When siblings are much older than their younger sibling (4 or more years), they engage in the greatest amount of nurturant and caretaking behaviour, and the least amount of conflict-related behaviour (Furman & Buhrmester, 1985). In agreement with this concept, Furman and Burhmester (1985) found that children were most satisfied with their sibling relationships when they had siblings that were much older than them as opposed to siblings that were only moderately older. Finally, a unique characteristic of sibling relationships is the concept of rivalry. Rivalry is a characteristic that does not emerge in studies of other relationships and may be related to perceptions of differential attention by parents which fosters feelings of conflict between siblings (Furman & Buhrmester, 1985).

The Implications of Living with a Relative with Mental Illness

This section explores how the healthy family described above is affected by chronic mental illness. Specifically, the negative impact of mental illness, burden and distress caused by mental illness, and the positive impact of mental illness are considered. Most research on this topic to date focuses on the implications of living with a mentally ill child, or a mentally ill young adult. Literature citing the implications of living with a mentally ill adult was considered irrelevant for the purposes of this study, and was excluded from the literature review. Additionally, most of the research in this section focuses on the implications of mental illness in Caucasian families. Families from different cultural backgrounds are affected by mental illness in a variety of different ways. In many cultures that perceive emotional expression as a sign of weakness, diagnosing mental illness is a challenge (Kirmayer, 1989). People with symptoms of anxiety and depression may not view their problems as psychiatric and may therefore reject treatment (Kirmayer, 2001). In China, for example, the incidence of depression is lower compared with that of North America, likely due to the perception that the social withdrawal associated with depression is caused by laziness, thereby affecting the willingness of the patient to seek treatment (Kirmayer, 1989). Although it is clear that cultural background impacts the diagnosis of mental illness and the willingness of the patient and family to seek and receive care, or share their experience with others, the purpose of this exploratory study was to examine the well sibling experience more generally. As such, the more general aspects of the impact of mental illness on the family are described below, and in absence of specific impacts faced by families of different cultures.

There is a general consensus among researchers that mental illness can have important negative consequences on the health of the family. Research on mental health shows that mental illness is distressing, not only to the patient, but to the entire family unit as well, as the impact of the mental illness may touch upon a broad spectrum of aspects of family life, such as work, leisure, income, physical health or relationships with others (Maurin & Boyd, 1990). The distress that mental illness places on the family can also affect the physical health of family members. Stress has been shown to adversely affect health in caregivers and other family members (Gallagher & Mechanic, 1996). Family members report tension, stress, anxiety, resentment, depression, physical ill health, feelings of hopelessness and an overall decrease in the quality of life as a result of having a seriously mentally ill family member (Doornbos, 1996). This distress affects physical health indirectly by depressing immune function, thereby lowering resistance to disease (Gallagher & Mechanic, 1996). Living with a mentally ill relative whose illness limits their activities is strongly correlated with poorer self-reported health among family members than among those families where the mental illness does not limit activities and independence (Gallagher & Mechanic, 1996).

Studies consistently show that mental illness produces a significant burden for other family members. The majority of this research has been conducted in the United States, Canada and Great Britain, however, the results show increased family burden regardless of population studied (Maurin & Boyd, 1990). This suggests that the demands placed on the family members of a mentally ill patient may have similar repercussions in many different cultures. In addition, many studies show a difference in level of burden experienced by family members due to gender. Females have been shown to be more distressed than males, possibly due to the fact that females are generally the primary caretakers of mentally ill patients (Maurin & Boyd, 1990). Mothers, specifically, tend to experience a greater level of distress than men, due to a greater sense of emotional isolation (MacGregor, 1994). In many cases, mental illness necessitates role and occupational changes for the primary caregiver, often meaning that a woman’s career options will be limited, with few financial rewards due to her caregiving role (Lefley, 1989). This process of role change can often leave women feeling underappreciated and can lead to negative health effects. Interestingly, the gender of the patient may also affect the level of burden experienced by other family members. Higher levels of burden are reported by families of male patients than by families of female patients. This may be due to the fact that mentally ill males tend to engage in more disruptive behaviour, such as substance abuse or violence, than mentally ill females, creating greater distress (Gallagher & Mechanic, 1996).

It has also been determined that families with other children experience more burden than households who live alone with the patient (Maurin & Boyd, 1990). This suggests that siblings may contribute to the level of burden experienced in a household due to the competing need for attention by the parents. The health effects of living with a mentally ill patient may also vary depending on the type of kin relationship being examined. Less normative kinkeeping, such as sibling caregivers, increases distress while fulfilling more normative caregiving obligations, like caring for parents, may actually yield gratification and happiness (Gallagher & Mechanic, 1996). Families with children may experience more burden than those without due to the caregiving tasks expected of parents. Caring for a mentally ill child at a time in life when parents expect independence from their children is a significant source of distress among parents, ultimately affecting their ability to care for other healthy children (Gallagher & Mechanic, 1996). The number of healthy children appears to make little difference, as living with someone who is mentally ill is negatively associated with the health and functioning of other family members, regardless of other dependent demands (Gallagher & Mechanic, 1996). Due to their developmental age, young siblings experience a special vulnerability to the mental illness in their families. A child who is confronted from birth with the mental illness of an older sibling experiences the losses of their brother or sister, and of their parents, whose energy is consumed by the mental illness. Similarly, siblings are especially vulnerable to the ability of the mental illness to undermine the acquisition of trust during infancy, development of peer relationships and academic skills during childhood, and the development of a secure identity during adolescence (Marsh & Johnson, 1997).

Parents often mourn the loss of their child’s premorbid personality, learning to let go of a life full of promise, and accept the patient’s possible abusive or assaultive behaviours, mood swings and unpredictability, patterns of losing and squandering money, and rejection of medications despite known patterns of relapse (Lefley, 1989). This experience of grief, or mourning, is a normal response to mental illness, but is not widely recognized, and therefore leads families to be misunderstood and further stigmatized (MacGregor, 1994). Family members may mourn for the relative they knew and loved before the onset of illness, but they also mourn the anguish of their family and their own personal losses (Marsh & Johnson, 1997). Unlike traditional grieving, family members rarely move through the stages of grief that culminate in acceptance. They are far more likely to experience continued feelings of grief and loss, resulting in continued distress for the family member (Marsh & Johnson, 1997).

There are many different types and degree of burden experienced by families. Families with less education and fewer financial resources experience more distress (Maurin & Boyd, 1990). Families frequently experience financial hardships due to medical bills and the patients' economic dependency on the caregiver, disruptions of normal household functioning, and lessened ability to work due to the demands of caregiving (Lefley, 1989). Doornbos (1996) agrees with this finding, stating that families often experience financial, marital, legal, employment, and housing issues, as well as relationship conflicts between family members. The progression of the patient's illness can affect the level of distress and disruption that is experienced by the family. Those families whose relative was currently stable experienced less distress than families in which the relative was symptomatic (Maurin & Boyd, 1990). Gallagher & Mechanic (1996) agree with this finding, suggesting that the severity, or level of disruptiveness of a mental illness, is correlated with the amount of negative health effects experienced by non-mentally ill family members, with severe behavioral problems having the greatest effect on the distress experienced.

Families also experience social isolation due to the mental status of their loved one. Social barriers are frequently erected against the households of patients. This social isolation and stigma stems from the fact that families of mentally ill patients were historically implicitly or explicitly blamed for the mental illness of their loved one (Doornbos, 1996). Parents experience guilt due to the sense of responsibility they have for their children's well being. This guilt is increased by a feeling of powerlessness and helplessness, exacerbated by the irrational fear that the parents somehow contributed to their child's illness (MacGregor, 1994). The behaviours of patients with severe mental disorders may further stigmatize the family, isolating the family, diminishing its reputation, and jeopardizing relationships with others (Lefley, 1989). Lefley (1989) also suggests that mental health professionals with mentally ill relatives experience a higher level of burden and social isolation due to perceived stigma from colleagues or disturbing contradictions between experience and training. This adverse experience of social isolation and stigma can lead to lowered self-esteem, damaged family relationships, risk of self-stigmatization, and feelings of isolation and shame (Marsh & Johnson, 1997).

Despite the negative consequences of mental illness on the family unit, the illness often offers families an opportunity to change in constructive ways. Families describe family strengths developed as a result of the mental illness, such as enhanced family bonds and commitments, expanded knowledge, and their role in the patient's recovery (Marsh & Johnson, 1997). In addition, family members speak about the resilience of their relative with mental illness. Families learn to overcome negative emotions, fears and attitudes, to balance multiple family needs, and to maintain supportive relationships and family stability, ultimately using personal resilience to turn the negative aspects of mental illness into both a learning and family growth experience (Marsh & Johnson, 1997).

The Impact of Mental Ilness on Siblings

Given the implications of mental illness on the family unit as described above, this section of the literature review focuses specifically on the impact of mental illness on the lives of siblings. There is strong evidence (Barlow & Ellard, 2006; Schuntermann, 2007; Sin et al., 2008) that suggests well siblings are affected in a multitude of ways by their chronically ill sibling; however there is a lack of general consensus as to whether or not the net effect is positive or negative. Results appear to be conflicting, as some studies have found adverse effects (Hastings, 2007; McKeever, 1983; Schuntermann, 2007), whereas others have reported that the ill sibling has little or no impact on the well sibling (Barlow & Ellard, 2006).

McKeever (1983) has noted that chronic illness places large demands on the family unit, and this often means that well siblings sense a reduction in parental attention and affection. The experience of parental neglect can cause the well sibling to become vulnerable, and may lead to increased behavioral problems and lack of sibling adjustment over time. Well siblings may act out to gain back the attention of their parents when they feel they are being neglected (Schuntermann, 2007). Behavioral problems are often seen in the well sibling when the ill sibling occupies most of the parents' time; however the extent of behavioral problems is related directly to those of the patient. Therefore, patients with more severe mental health impairments appear to put their well sibling at an increased risk for developing behavioral problems (Hastings, 2007). The severity of mental health impairment is also related to the level of burden that the family experiences. More severe conditions place stronger financial strain and increased stress on the family unit, and likely contribute to a greater disruption of normal family life. This disruption greatly affects the well sibling and can lead to behavioral problems and poor adjustment into normal life (Loukissa, 1995). The context of the illness and caregiving burdens increase stress among parents and primary caregivers, and can lead to both marital strain and depression among parents. Parental unhappiness places undue burden on the well sibling and can affect the parents' ability to provide adequate support to their healthy child. This evidently has a negative impact on the well sibling (Cohen, 1999).

Research has also suggested that the experience of living with a mentally ill sibling can actually foster positive experiences in the well sibling. Siblings describe both positive experiences for their family unit, as well as for their own personal development. Many well siblings have expressed that the experience of having an ill sibling has not only made them a much stronger, understanding and considerate individual, but it has also brought their family closer together and has fostered a family environment which is cohesive and resilient (Sin et al., 2008). Research also shows that siblings of children with mental health issues may have enhanced coping skills. Moreover, the well sibling can have a positive influence on the behavior of their ill sibling. Siblings have increased positive outcomes when they are included in the patient's care and are able to help their parents (Schuntermann, 2007).

Throughout the available research, it was suggested that siblings experience stress and confusion when asked about their ill sibling (Stålberg, Ekerwald, & Hultman, 2004). Parents often try to shelter their children, or protect their family's image, and do not provide adequate education about the ill sibling's condition. Thus, when siblings are asked about their ill sibling, they are poorly informed about the health condition (McKeever, 1983). Although well siblings may have limited information regarding their ill sibling's condition, they benefit greatly from pyschoeducational groups, where they are able to gain support in addition to knowledge about mental health conditions and coping strategies. Siblings who attended these groups showed fewer signs of depression and improved relations with their ill siblings (Loukissa, 1995). The results of the study conducted by Loukissa (1995) suggest the need for both education and support for well siblings concerning their ill sibling's conditions.

Effective Care for Familial Mental Illness

The presence of mental illness in the family has many implications for the success of family dynamics, as well as for the lives of the well sibling. This section of the literature review describes how families adapt successfully to mental illness. It includes a discussion of support and educational resources, and concludes with a discussion of the frustration many families face in attempting to access these resources.

Social support is seen as one of the most important factors for preventing distress in families where there is mental illness. Increased satisfaction with social support networks serves to decrease burden (Maurin & Boyd, 1990). Patients with a support system have also been shown to be less of a burden to their families than those without a support system (Maurin & Boyd, 1990). This evidence suggests that two levels of support systems are required, one for the family members, and one for the patient, in order to effectively reduce the level of burden experienced by all family members. Lefley (1989) suggests that involvement with a support group is one of the most important services that can be offered to families of mentally ill patients. Research firmly states that social support is not only crucial for the patient, but also for the family in order to create a healthy outcome, as they work through their feelings of grief and loss (MacGregor, 1994). Grieving is a social event and as such, it requires interaction and validation from others (MacGregor, 1994). Policies that improve support and care for families caring for mentally ill patients can significantly improve the lives and health of family members. Policies which make it easier to receive supportive assistance and respite care help families cope, by reducing the level of burden and by improving physical health of family members (Gallagher & Mechanic, 1996).

Educational resources are also important for reducing burden to a family. Educational programs designed to reduce stress and improve quality of life for patients' relatives have shown some success (Maurin & Boyd, 1990). Education on symptoms and medications and behavioral management techniques are the most important services that can be offered to families (Lefley, 1989). Educational resources or programs which provide information regarding mental illness, symptoms, causes, treatment, family roles, and resources available to the family have been found to be effective in producing positive family outcomes (Doornbos, 1996). Numerous studies have shown the beneficial effects of family education, such as increased knowledge about serious mental illness, greater acceptance of the illness, enhanced family relationships, and enhanced coping skills (Lefley, 1989; Loukissa, 1995; Marsh & Johnson, 1997; Maurin & Boyd, 1990).

In general, support for families although present, seems to be inadequate. Surveys of American families indicate general dissatisfaction with the ability of the service delivery system to treat persons with mental illness (Lefley, 1989). Families report frustration in attempting to elicit answers to questions, suggesting that they are not receiving adequate education surrounding the health of their loved one. In addition, families often state that mental health professionals are reluctant, ambiguous, or sometimes even hostile in their communications with family members (Lefley, 1989). Families also report unsatisfactory handling of crises and emergencies, insufficient communication and availability of professionals, absence of programs and services for families, and lack of involvement of family members in treatment planning for the patient (Marsh & Johnson, 1997).

Summary of Literature Review

This literature review examined the attributes of healthy family dynamics, and then explored how these healthy families are affected by the presence of mental illness. The impact of mental illness specifically on siblings was further explored. The literature review concluded with examples of effective care and resources for families in which there is mental illness. The frustration families face in finding or accessing this care was also discussed. It is important to note the paucity of recent work on the subject of healthy family dynamics, and effective care for familial mental illness. Much of the literature on the aforementioned subjects is quite old and suggests the importance of further research in the field. Given the additional lack of evidence about the well sibling experience of mental illness, it is clear that this thesis study has the potential to contribute new knowledge to the field, and indicates the need for further research.

There are several gaps in knowledge pertaining to the well sibling experience of living with a mentally ill sibling and the effect on the family unit. Barlow and Ellard (2006) performed a meta-analysis of current research and noted the lack of longitudinal studies in this field. While individual interviews are valuable, it is important that research highlight how the sibling experience can change over time. The greatest deficit in the current research is that well siblings' experiences are rarely represented from a first-person account. Descriptions of well siblings in families are often based on observation, or parental interpretations (McKeever, 1983). Hastings (2007) also expressed the need for research to address well siblings' own perceptions of their experiences, as parental interpretations may be inaccurate due to rating bias. Finally, in the study conducted by Sin, Moone and Harris (2008), all of the siblings interviewed expressed the desire for an opportunity to talk about their experiences and how their sibling's illness had affected them. These siblings reported that such an opportunity to voice their experiences does not currently exist. Without firsthand accounts from well siblings, it is extremely difficult to gain a complete and realistic understanding of how chronic mental illness affects the sibling relationship. Given the paucity of first person qualitative research of the well sibling experience, this study aims to bridge this gap by contributing to what is known about the well sibling experience of living with a sibling with anxiety and/or depression.

In summary, very little research has been conducted in terms of the effect that an individual's chronic mental health disorder has on their well sibling. Current information that does exist on this topic is based mainly on observation, or from the primary caregiver (parent) perspective, and not on the personal experience of the well sibling (McKeever, 1983). Research is also conflicting, stating that the ill sibling's condition can have either negative or positive effects on the well sibling. Finally, current research also indicates that siblings who attend educational and support groups have fewer negative outcomes, thus indicating the importance of these groups (Loukissa, 1995).

Research Questions

Given the lack of evidence in general about the experiences and effects of mental illness on well siblings, and specific lack of firsthand accounts from well siblings, it is important to gain a more in-depth understanding of their lived experience. This thesis study thus intends to address the current gap in literature by investigating the experiences of young adults who have a mentally ill sibling, in order to shed light on their personal experience and offer recommendations for improving the support and informational resources offered to this group. The question that will guide this research about the sibling experience is as follows: *From their personal perspective*, *what is the lived experience of young adults who have a sibling with chronic depression and/or anxiety?*

This research will not only enhance the existing research by offering firsthand accounts from well siblings but it will also function as an opportunity for well siblings to share their experience with peers. This research aims to shed light on both the positive and negative effects of the ill sibling's condition on the well sibling by interviewing a diverse sample and including firsthand reports of experiences. From the results, key messages and recommendations will be developed for other well siblings who can learn from others' experiences, which may help to support their decision-making about options for support. Given that existing support groups are mainly focused on primary caregivers, the information from this investigation intends to contribute to useful resources for siblings, providing them with support, validation of shared feelings and the potential to normalize their experiences.

To address this research question, three specific objectives are described:

1. Explore and describe experiences of well siblings as young adults where there is mental illness in their families
2. Identify key messages and key resources for families based on the range of experiences collected from this exploratory study
3. Develop key messages and recommendations for healthcare professionals to improve access to support from health and social services for this group

Methods:

Overview

For the purpose of this thesis project, an inductive qualitative descriptive research design was adopted, using narrative inquiry within semi-structured focus groups, to collect primary data regarding the experiences of well siblings who have a mentally ill sibling. A qualitative approach was considered appropriate given the nature of this study's research question and objectives, which are defined above – where the experiences, feelings and perspectives of participants were being sought to understand a phenomenon rarely studied to date. This study was approved by the McGill Faculty of Medicine Research Institutional Review Board in January 2014 as research conducted for an original Master's thesis.

Research Setting and Context

The work for this thesis was conducted as an exploratory project to inform future health experiences related research conducted by the health experiences research team based at St. Mary's Research Centre in Montreal, Quebec. St. Mary's Hospital is a small community hospital with 271 adult patient beds located in the heart of Montreal. St. Mary's serves a diverse cultural community that comprises over 50 different languages, including English and French. St. Mary's is also a McGill University affiliated research center that focuses on health services research and primary care. McGill University has a teaching hospital network, containing nine hospitals, of which St. Mary's is included. This teaching hospital network is an integral part of the research, teaching, and clinical activities of the Faculty of Medicine. Each of these institutions is closely integrated with McGill University and form the basis of the clinical departments of the Faculty of Medicine.

This initiative is part of a larger international collaboration, involving research teams in fourteen countries worldwide, all using the same qualitative research methodology to document and share people's personal experiences of health and illness through an online resource. The Health Experiences Research Group (HERG) at the University of Oxford, UK, originally developed this approach in 2001, and created an evidence-based health website (www.healthtalkonline.org) to provide supportive and educational resources for people with similar conditions, as well as for healthcare professionals (for an overview of the UK approach and history (Herxheimer et al., 2000). This website allows people to see, read and hear text, audio and video clips from semi-structured interviews with people from across the UK about their experiences with a wide variety of different health and illness topics. Each module uses maximum variation sampling techniques in order to cover the broadest range of possible experiences for each topic (Herxheimer & Ziebland, 2004). The site also provides links to reliable evidence-based information and resources that are relevant to each online module, or health-related topic. In addition, the site is used in several clinical contexts in order to teach communication techniques to physicians. Currently the UK website features over 75 different topics, with over 25,000 video and audio clips, and receives more than 2.2 million site visits a year (DIPEx, 2013).

The health experiences team at St. Mary's has developed a Canadian version of this website with seed funding from the Hospital Foundation to develop the first two modules. The first Canadian module has been launched (www.healthexperiences.ca) and focuses on caregivers who care for adults with a chronic physical illness. The second module is in development, and will explore women's experiences with breast cancer. A third module has received partial funding from the Bell Canada Community Fund and will explore new immigrants' experiences with mild depression and anxiety.

The creation and ongoing development of the healthexperiences.ca website offered a unique opportunity to explore the experiences of young adults whose families were afflicted by mental illness – the particular interest of the author (in the context of a Master's thesis) was that of exploring the perceptions and experiences of well siblings with a mentally ill brother or sister suffering from anxiety and/or depression.[1] A preliminary scan of the existing literature exposed this area as a relatively unexplored phenomenon. This thesis aims to contribute insight and information for further research into mental health-related experiences of young adults, and towards improved support and educational resources for well siblings.

To address the research questions, the author held three focus groups with well siblings (healthy volunteers) in the winter of 2014 at McGill University Campus in Montreal, Quebec. Participants were recruited from within the McGill University community in Montreal, Quebec. McGill University is a large Canadian university with over 39,000 students. McGill has a very international student body, with over 22% of the student body coming from countries other than Canada.

Theoretical Framework

This research was not based upon a theoretical framework but rather employed an inductive approach. Inductive approaches are used to guide the research of understudied phenomena when there is no predefined theory with which to align the research inquiry (Maxwell, 2012). An inductive approach entails reading and re-reading the data in order to identify themes and sub-themes. In an inductive approach the themes emerge from the data itself, instead of situating the data in a pre-identified framework (Pope, Mays, & Ziebland, 2000). The study of patients' experiences with various health conditions is a relatively new field with no agreed upon methodological or theoretical basis, and therefore an inductive approach was appropriate (Ziebland & Wyke, 2012). Given the lack of existing research in regards to the sibling experience of mental illness, this investigation aimed to produce valuable knowledge in an understudied field.

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[1] The author has a younger brother diagnosed with both anxiety and depression.

According to Maxwell (1996), an inductive framework is the most appropriate design for this research because of the lack of current information available.

Research Design

This research follows an inductive qualitative descriptive design, using a narrative research approach with an interpretative phenomenological lens to explore the personal experiences of well siblings living with a chronically mentally ill brother or sister. Interpretive phenomenology was chosen in this case as it allows the researcher to examine the narratives of well siblings to gain a greater understanding of their personal perception of the effect that an ill sibling's condition has on their own life. This was the most appropriate research methodology for this project, as the author was concerned with understanding the beliefs and experiences of the well sibling (Smith, 1996). Therefore, other methodologies would have been less suitable for this research, as they would have failed to explore the in-depth embodied experience of the sibling relationship (Benner, 1994). The aim of interpretive phenomenology is to explore the participant's view of their experience and to adopt as far as possible, an "insider's perspective" (Smith, 1996). This was exceptionally important for this project, as we conducted an exploratory inquiry to gain an in-depth understanding of the personal experiences of well siblings. This was done in order to gain an intimate perspective of how the well sibling is affected by living with a mentally ill sibling. This project used a phenomenological lens to examine the personal narratives of well siblings. Narrative research involves the telling of stories by participants and the subsequent analysis of these stories. Life is understood as and shaped by narratives, and as a result, narrative research parallels the way individuals inquire about experiences (Sandelowski, 1991). Narrative research is used to explore individual and group stories of particular life episodes or experiences (Sandelowski, 1991). In this case, the well sibling experience of living with a mentally ill sibling was explored.

Focus groups were used to collect the participants' personal experiences of living with a mentally ill sibling. Focus groups are group interviews consisting of anywhere from fewer than four people, to ten participants or more (Asbury, 1995). These interviews are designed to obtain several individuals' perceptions of a defined area of interest in a welcoming, non-threatening environment (Casey & Krueger, 1994). Focus groups were chosen as the most appropriate data collection method for this research as they elicit a warm and supportive environment, which was considered beneficial due to the lack of existing supports available to well siblings. Focus groups also offer empowerment to participants through shared experiences and a chance to normalize their experience, thereby lessening the impact of discussing sensitive topics, such as an ill sibling. Focus groups can also be used to explore new areas of research from the participants' own perspectives (Asbury, 1995). Given the lack of existing research in this field, focus groups were an appropriate method for collecting data surrounding the experience of living with a mentally ill sibling. Additionally, due to the exploratory nature of this study, focus groups were a more appropriate choice than individual in-depth interviews, which would have entailed a longer period of research extending beyond the two-year master's program requirements.

Participants

The participants for inclusion in this study were healthy young adults (ages 18-25) living with a chronically mentally ill sibling. Young adults (ages 18-25) were selected as the participant group for this study because they are able to give informed consent and are at the stage of development where they may be trying to make sense of their experiences. Given the additional ethical requirements and implications of involving minors (under 18 years) in research, we chose to focus on young adults 18 years old and over. The age range employed in this thesis study is a typical age category (18-25) for young adults (Arnett, 2000), and is consistent with the age range employed by many of the studies cited in the relevant literature (Schuntermann, 2007; Sin et al., 2008).

The aim was to recruit a diverse sample of 15-20 participants. Due to the exploratory nature of this study, a convenience sampling technique was employed, including those individuals most able to contribute to the aims of the study, and those who were available and willing to participate. This type of sampling is adequate for small, exploratory studies like the one used in this thesis (Anderson, 2010). A chronic mental health condition in the context of this analysis was defined as a medically diagnosable mental health condition with duration of six months or longer, which is relatively stable or shows a slow progression (Barlow & Ellard, 2006). For both methodological and logistical reasons, the inclusion criteria were further narrowed to those participants living with a sibling experiencing depression and/or anxiety, as defined by the well sibling (for a more descriptive definition of anxiety, depression, or family, please refer to the Introduction of this thesis). Research suggests a likely relationship between the sibling experience and the severity or type of illness (Gallagher & Mechanic, 1996; Hastings, 2007). The inclusion criteria for diagnosis were narrowed due this relationship, and the perceived difficulty in interpreting results given the scope of this exploratory study if broad diagnostic inclusion criteria were adopted. Anxiety and depression were chosen in this case as they are considered the most common mental illness diagnoses in Canada (Zoutis, 1999).

The objective of this study was to understand the experiences of healthy young adults who have a mentally ill sibling. Because the focus was on the perceptions of these healthy siblings, we based eligibility on a participant's perception that their sibling had a mental illness. It was the self-reported experience of living with a mentally ill sibling that was of interest and importance, rather than an investigation of how a particular diagnosis affects siblings and families.

Recruitment targeted well siblings with a range of ages and backgrounds, different educational statuses, and areas of study. Well siblings that were targeted for recruitment also had a variety of family situations that included having multiple siblings, having an older or younger mentally ill sibling, and having one-parent or two-parent homes. Following the first 10 volunteers, recruitment efforts were expanded to diverse venues to ensure that recruitment materials reached a variety of potential participants. Additionally, the screening tool allowed for the selection of volunteers that were diverse in age, background and family situation.

Broad inclusion criteria for participants were adopted to obtain diverse information about how well siblings are affected by their ill sibling's condition. Participants were those individuals currently living in the Montreal area and from within the McGill community, as recruitment only took place at McGill University. Recruitment and screening strategies were used to generate as diverse a sample as possible, and therefore family experiences that were considered 'typical', but also those, which might be considered 'unusual', were considered (Patton, 2005). An example of an unusual family experience might be considered a family in which the well sibling was acting as the primary caregiver for their ill sibling.

Exclusion criteria for the selection of participants included well siblings who did not speak English. English did not have to be the primary spoken language of the participants, but they had to be proficient enough in English to participate fully in the focus group discussions, as the focus groups were facilitated in English. English proficiency was assessed by the participants' ability to communicate effectively in English during the screening call performed by the author. Participants had to be free from diagnosed mental illness themselves in order to satisfy the "well" sibling criteria. Participants who identified as being "well" satisfied this criterion, as it would have been beyond the scope of this study to verify the mental health status of the participants. Participants were required to be between the ages of 18-25 at the time of recruitment, however it was possible for participants to have had experience living with a mentally ill sibling from the age of 17 or younger.

Participants were recruited through the McGill University network. Participant packages were distributed to key contacts from the existing professional network of academic colleagues provided by the thesis committee. These key contacts helped to recruit participants by posting information posters in classrooms and common student areas around the McGill campus such as: the gym, libraries, residences, cafeterias, various student lounges and academic buildings. The recruitment poster was also circulated through an e-mail lit serv of McGill students who attended a student-run conference for promoting mental wellness on campus,[2] as well as through various other organizations on campus. For a full list of the recruitment strategy please refer to Appendix 3. Interested participants contacted the author by telephone or email to express interest, and the author arranged to speak with them by telephone to screen their application and ensure eligibility (Appendix 4). Well siblings who volunteered for the focus groups were provided a sum of $20 towards their time and any related expenses, to cover reasonable costs associated with travel to/from the meeting and parking, as well as possible lost wages during the time of participation in the group discussion.

Data Collection

The narrative approach and interview questions developed for the focus group sessions were guided by the protocol developed by the University of Oxford Health Experiences Group (DIPEx UK), given that this research focuses on individuals' perspectives about their lived experiences, and to be consistent with the methods adopted for other health experiences modules within the research team. The primary method of data collection was through three focus groups. For the purposes of this research, the size of the focus groups was limited to five to six participants in each group. This number kept the focus groups small enough to allow participants to comfortably express themselves without feeling overwhelmed, but also ensured that the groups were large enough to facilitate meaningful group discussion. Focus groups can take a variety of structures and forms; however, the focus groups used in this study were semi-structured in nature and followed the protocol for collecting personal stories about health experiences developed by DIPEx UK. The focus groups were held in an informal setting and were moderated by a lead investigator (MSc candidate) and co-facilitator (MSc supervisor: Dr. Susan Law). In preparation for the focus group sessions, the author created an interview guide with questions and prompts

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[2] Students in Mind (2013, October). Students in Mind Conference, McGill University, Montreal, Quebec.

(Appendix 5) that followed a narrative approach (Mishler, 1991), allowing each participant to "tell their story" about living with a mentally ill-sibling, followed by discussion amongst the group around a limited number of key questions.

In the weeks prior to the focus group meeting, participant information packages containing a recruitment poster (Appendix 2) and the consent form (Appendix 1), were distributed to participants via email. The consent forms were written in lay language and provided information about the purpose of the study, the rights of the study participants, what they could expect from participating in the study, the benefits and risks of the study, voluntary participation and withdrawal in the study, confidentiality, as well as the contact information for the study investigators and the St. Mary's Hospital Ombudsman. The participants were asked to read over the consent form and to ask any questions that they might have at the focus group meeting. On the day of the focus group, the meetings began with a short discussion of the consent form, allowing participants to ask any necessary questions before signing the form. Following the signing of the consent form, the facilitators discussed group dynamics, highlighting the importance of creating a "safe space" free from judgment. For a complete overview of the focus group sessions, refer to Appendix 5.

Focus Groups

The first focus group followed a participatory approach, engaging participants in the discussion and design of the research tool, where we tested and developed the final interview guide to be used with the subsequent 2 focus groups. This ensured that the questions asked were relevant and meaningful to the well siblings being interviewed.

After the participants signed their consent forms, which included permission to audio-record the focus group session, the facilitators provided an introduction to the MSc thesis research of sibling experiences of mental health, the purpose of the focus group in which they were participating, as well as an introduction to the research team members. The author (lead facilitator) then led the group through the questions and prompts for the session. The first part of the session involved the telling of each participant's personal story of his or her experience living with a mentally ill sibling. To guide this part of the focus group, the lead facilitator asked each participant to present an overview of their personal experience, which helped to identify the participant's own concerns, meanings and priorities (Herxheimer et al., 2000). Following each participant's brief narrative, the facilitators led the group discussion by using the prompts outlined in the focus group moderator guide (Appendix 5). The facilitators asked the group to reflect on how each participant's story was similar or different, and what they learned by hearing other people's stories.

The second part of the focus group was related to the experience of living with a mentally ill sibling. Participants were asked to describe this experience in three words. The facilitators then prompted the participants by asking them to categorize their experience as overall positive or negative. The participants were also asked to discuss how their ill sibling's condition affected their own health and how they managed this. During this phase, participants were given the unique opportunity to discuss their personal experiences but also to share in each other's different situations to see that they were not alone and that other participants shared their sentiments.

The next part of the focus group centered on information and support. Participants were asked to discuss the type of information that they received from parents, clinicians and other sources about their siblings' condition. They reflected on the level of information that they received, and discussed particular topics that they wished they had received more information about. Participants then spoke about the support they received from family and friends, or from professionals. The facilitators used prompts to discern who provided the support and whether or not the participants felt the support they received adequately addressed their needs. The participants then discussed how they felt education and support could be improved.

The final phase of the focus group explored advice from the participants. The participants were asked to offer advice to other young adults living with a mentally ill sibling, as well as to parents. The participants were also asked to give advice to the people running or working in the healthcare system. In the first focus group following the discussion of advice to others, facilitators asked about the content of the focus groups, and whether the participants felt it addressed the experiences and needs of well siblings. Participants gave their suggestions for subsequent focus groups, and additional prompts were added to the facilitator guide for the following two focus groups.

It is important to note that a list of counseling and health services resources was available to those participants requesting or necessitating further support during the focus group discussions. This list (Appendix 6) contains resources specific to the McGill community, as well as other resources available to the general public in Montreal.

Focus group participants were told that the session would take approximately 45 to 90 minutes to complete. Following the sessions, the lead facilitator took notes about the broad overall themes that emerged during the group discussion. The focus groups were audio-recorded and were subsequently transcribed by the lead facilitator.

Data Analysis

The focus group audio recordings were transcribed by the author, in order to promote greater familiarization with the data (Braun & Clarke, 2006), and the transcripts were then reviewed by both the author and the co-facilitator (S. Law). Qualitative data analysis began within the focus group sessions as the facilitators processed the comments, asked follow-up questions, and summarized recurring ideas throughout the session (Casey & Krueger, 1994). As outlined by Asbury (1995), a standard semi-structured guide was used to promote consistency between focus groups and to assist with facilitating the group discussion. Immediately following the focus group sessions, the author wrote down a summary of each session, including details about group dynamics, initial observations and interpretations (Casey & Krueger, 1994).

Transcripts were then analyzed using an inductive thematic analysis of the participants' narratives (Braun & Clarke, 2006; Patton, 1990). This approach was chosen for the analysis to identify the issues that were important to the individuals living with a mentally ill sibling, and not simply those, which the research team and health professionals deemed important. In this case, the content of the narratives was of more interest than the delivery of the narratives, and thus thematic analysis was appropriate (Riessman, 2008). By following Riessman's method of thematic analysis, the narratives were examined to identify and group together common experiences faced by well siblings. This approach is data-driven, meaning that data is coded based on the content of the focus groups transcripts, and not a pre-existing framework (Braun & Clarke, 2006). The analysis phase of the research followed the six phases of analysis outlined by Braun & Clarke (2006) in order to ensure that rigorous thematic analysis was achieved.

The data from the transcripts was first reviewed by the author using pen and paper to note keywords and emergent themes in the margins of the transcripts (Casey & Krueger, 1994), followed by a more thorough analysis using Microsoft Word. The coding and analysis of the text was conducted in order to organize and identify emergent themes as well as those that were anticipated from the findings of the literature review, using the method of constant comparison (Pope et al., 2000). The author conducted a preliminary data analysis of the first and second transcripts independently; as did the MSc supervisor, and results of the analysis were compared and discussed together to develop the coding frame to be applied to the third transcript, and to resolve any discrepancies. The thesis committee was consulted periodically to discuss preliminary results and emergent themes arising from the data, as well as to resolve any methodological concerns. A final review of the transcripts was undertaken to identify illustrative quotes within the themes and sub-themes.

Data collection and analysis were not carried out until data saturation was achieved, as the objectives of this thesis were to conduct a brief exploratory study, and data saturation was unlikely within the context of research conducted on this topic for a Master's thesis. Data saturation refers to the iterative process of data collection and analysis, whereby data is collected until no new codes emerge

(Green & Thorogood, 2013). While data saturation is required for studies employing a grounded theory methodology, briefer more descriptive studies may still be considered methodologically sound in the absence of saturation if they employ prolonged and intensive data collection and analysis phases (Green & Thorogood, 2013).

Results:

A qualitative thematic analysis of the written transcripts and observational notes taken by the author during the focus groups identified six major themes that emerged from participants' experiences: impact of illness on family dynamics; role of the well sibling; positive impact on well sibling; negative impact on well sibling; information, support, and professional services; and advice to others. Several subthemes were identified within these broad themes (see Appendix 7 for a detailed list of themes and sub-themes). An overview of the processes and composition of the focus groups is outlined below followed by a presentation of the findings within each of the themes.

Focus Groups and Participant Characteristics

Ethics approval was received from the McGill IRB in January 2014 and then recruitment began immediately. Three focus groups were conducted during the months of February and March 2014; all were held in the afternoon at times convenient for the participants (early or late afternoons) in private meeting rooms at McGill University in Montreal, Quebec. A total of 40 people expressed interest in participating within 5 weeks of sending out notices of the study. Posters were removed at this time, and notices in e-mail list servs were discontinued. The author contacted the first 25 people who responded to the recruitment notices, and of these: 17 were selected to participate in the focus groups, 3 individuals did not fit the study criteria (were 34 years old and well above the age range; could not participate in English; and did not appear to meet the eligibility criteria due to sibling situation), 2 people chose not to participate after learning more about the study, and 3 people declined participation as they were unavailable for the selected focus group dates. Interest in the study was unexpectedly high, and 15 additional participants who expressed interest following the first screening were put on a waitlist pending a decision about holding additional focus groups beyond the number indicated in the protocol for this study.

Focus groups were organized in terms of availability of the participants so that there were five to six participants per group. Two focus groups had six people, while one focus group contained five participants. At the start of each session, the author and the focus group moderator (SL) provided a brief overview of the study, and participants were invited to sign the consent form (all consented) and give permission for the focus group sessions to be recorded (none objected). The focus group discussions each lasted between 60 and 90 minutes. Participant characteristics are presented in Table 1, while the quotation coding scheme and details of each individual participant are presented in Table 2. The majority of participants were female (65%). Participants came from varied familial backgrounds: some had an older ill sibling who was reportedly depressed or anxious (53%), while others had a younger ill sibling (35%), and some participants had multiple mentally ill siblings (12%). All of the participants were students attending a CEGEP (Collège d'enseignement général et professionnel/General and Vocational College) (6%) or University in Montreal, Quebec (94%).

While some participants were born in Quebec (29%), most of the participants were born in another Canadian province (59%). In addition, most of the participants (14 of 17) self-identified as Caucasian. Therefore, since the majority of the participants were born in Canada (88%) and self-identified as Caucasian (82%), there was only minimal ethnic cultural variation among participants in this study. Although the participant screening tool (Appendix 4) asked participants to self-identify their ethnic background, cultural variation of the well sibling experience was not a distinct topic or theme mentioned in these particular focus groups and therefore does not appear in the results below. The lack of cultural variation found in these results may not be reflective of the prevalence of mental health problems amongst young adults or well siblings' experiences in general, and is therefore discussed in further detail in the limitations section of this thesis.

It is of interest to note that each of the focus groups sessions had excellent group dynamics. Participants were all very respectful of one another, and listened intently as each person spoke. There were minimal interruptions or speaking over one another, and only one participant became visibly emotional while telling her story. She was invited to take a break from the group, but chose to stay and continue to participate in the discussion. In addition, the majority of participants (12 of 17 – 71%) indicated that they had learned about the study through e-communication, either through e-mail or a social media network.

Table 1: Focus group participant characteristics

Participant Characteristic	n	%
Sex		
Female	11	65
Male	6	35
Age		
18-19	4	23
20-21	9	53
22-23	2	12
24+	2*	12
Place of Birth		
Quebec	5	29
Other Canadian Province	10	59
Outside of Canada	2	12
First Language		
English	14	82
French	1	6
Other	2	12
Self-Identified Ethnicity		
Caucasian/White	14	82
Southeast Asian	1	6
South Asian	1	6
European Origin	1	6
Family Situation		
Younger Ill Sibling	6	35
Older Ill Sibling	9	53
Multiple Ill Siblings	2	12
Reported Illness of Sibling		
Anxiety	5	29
Depression	7	41
Anxiety and Depression	3	18
Bipolar Disorder	2	12

*Although the age range in recruitment materials was 18-25, the author, in consultation with her supervisor and advisory committee, agreed to include two participants who were slightly older (26 and 27) given that their experience with a mentally ill sibling was relatively recent and during a time that included the age range for recruitment.

Table 2: Individual participant characteristics and identifying codes

Please note the following procedure regarding the participant code: FG stands for focus group identifier (one of three), and F/M stands for female or male, with the following number identifying each unique participant.

Participant Code	Gender of Participant	Gender of Ill Sibling	Type of Ill Sibling
FG1F1	Female	Male	Younger
FG1F2	Female	Female	Younger
FG1F3	Female	Female	Younger
FG1F4	Female	Female	Younger
FG1M1	Male	Male	Older
FG1M2	Male	Female	Older
FG2F1	Female	Female	Older
FG2F2	Female	Female	Older
FG2F3	Female	Female	Older
FG2M1	Male	Female	Older
FG2M2	Male	Male	Younger
FG3F1	Female	Male	Older
FG3F2	Female	Male/Female	Both Older
FG3F3	Female	Female	Younger
FG3F4	Female	Female	Older
FG3M1	Male	Female x2	Both Older
FG3M2	Male	Female	Older

Theme 1: Impact of illness on family dynamics

This first theme focuses on the impact of the sibling's illness on family dynamics. Participants described a wide range of different sorts of family relationships and dynamics, both good and bad, between themselves, their ill sibling, and their parents. Participants also spoke about their perceptions of the impact the illness had on their siblings' relationship with their parents. Additionally, changes in behaviour of family members over time and the resulting impact on family dynamics were described. These varied family dynamics are presented below in four sub-themes.

Theme 1A: *Relationship with ill sibling*

All of the participants spoke about their relationship with their ill sibling before the illness, and described how they felt their siblings' illness affected this relationship. Most participants reported that a close relationship with their sibling prior to the onset of illness made it more difficult to accept the diagnosis, whereas others found a close relationship with their ill sibling made it easier to accept their diagnosis:

> *"Yeah, it was—the difficult part was that my brother and I were very, very close, our whole lives. We still are." [FG1F1]*
>
> *"And, me and her are super close, like she's one of my best friends, and we talk every single day. So its like, it's good."[FG1M2]*

Participants described how despite a close relationship with their sibling, they were often kept in the dark about their siblings' illness and further described the hardships they continue to face:

> *"Well, my sister and I um, we were very close and we can tell each other everything but, growing up she never told me about her anxiety disorder." [FG1F4]*
>
> *"...so even though we're really close, like, now it's like, like I can tell her everything that goes on in my life but she can't tell me hers, and, she keeps—for example, I found out recently that she also attempted suicide." [FG1F4]*

A few participants also described how their relationships with their ill sibling had improved over time. These participants described how they believe they may not have had this opportunity to strengthen their relationship had their sibling not been diagnosed with a mental illness:

> *"...when she was first diagnosed, I started communicating with her daily. And now, she's become one of my best friends and I don't know if that would have happened otherwise." [FG1M2]*
>
> *"...her relationship with me has really improved. We were never really close, I didn't really understand what was happening, I just thought she was being mean to me, but it like—after she moved out we started to hang out on our own instead of being forced to live in one house with one another. And, um yeah, we became—we've become closer over the years since she's resolved it."[FG2F3]*

While some participants described a close relationship with their sibling, or one that has gotten closer over time, many participants described a distant relationship with their ill sibling, some with a negative impact, some with little impact – but sometimes within a deteriorating family situation:

> *"...we were fine like, let's say a few months earlier and then as soon as everything started to sort of happen and it just—like, my parents relationship deteriorated, my sister's relationship with my parents*

> *deteriorated, my relationship with my sister really deteriorated. I didn't really talk to her much. I didn't spend much time with her." [FG2M1]*
>
> *"Um, well, I was never very close with my sister. Um, we had started to become closer when she moved out of the house, but then my parents forced us to live together our relationship really deteriorated. Um, we talk maybe once every two months for about five minutes now. We don't get along."[FG2F1]*
>
> *"…because of the way she acted, I never really like, got to understand her very well, like and cause of our different interests." [FG3M2]*
>
> *"…whenever I go home to visit and stuff, she's been really angry. Like, still. Um, it's really bad. Like two weeks ago—three weeks ago I think, um, I was home and my parents were out of town, and it—so it was just me and my sister and I—she like, physically would threaten me and stuff, and I—I left (city in Canada) like, I couldn't be around her."[FG3F4]*
>
> *"Um, I've never really been that close to him. Uh, I don't really talk to him unless I go home. Um, so, most—mostly it's been a struggle for my parents, not so much for me. And, I think that's partly why we were so distant growing up, just cuz I couldn't really relate to him with all of his problems." [FG1M1]*

Participants also described how they believe their sibling views their relationship and the level of support that they offer. These participants also spoke about the difficulty they believe their sibling has following in their footsteps.

> *"Um, I feel like she doesn't think that I'm supportive. But she also feels as though she can talk to me." [FG1F4]*
>
> *"I think my sister thinks I'm supportive. I mean she often comes to me and like, talks to me about that—about things but at the same time like, she keeps on saying like that she doesn't want—she feels like she's like living in my shadow pretty much" [FG1F2]*

Although many participants described difficult relationships with their ill sibling, most appeared to remain optimistic that the relationship might improve in the future.

Theme 1B: ***Relationship with parents***

Most participants described their family situation as positive and supportive:

> *"…we grew up in—in what was kinda I guess considered a pretty normal household…good family life, good support from our parents…" [FG2M2]*
>
> *"…my Dad's not that great at calming me down when I'm stressed, so I have like, a different relationship with him, but in terms of my Mom, definitely it's gotten a lot closer." [FG3F2]*

Participants who experienced a close relationship with their parents also expressed concern for their parents' well-being:

> *"...the last few years have been kinda broken promises and a lot of lies to my parents and—and that's what bothers me. Not so much how he treats me, because I can—I can deal with that, I can handle that, but it's how—it's how he you know, how he treats my parents." [FG2M2]*
>
> *"...my biggest issue with the whole thing was how my parents were treated and I felt it was just so disrespectful and so cruel what he was doing to them."[FG2M2]*
>
> *"...whenever I've talked to her I'm like, "are you taking time to you know, go for your runs and to watch TV", cause you have to step back for every so often and—and I think it really helps."[FG3M1]*

Although many participants expressed how they felt protective over their parents, they also explained how their parents tried to protect them:

> *"...her main objective was to kind of to protect me from it, and I think that was really transparent to the other side of the family and I think they were offended by that."[FG3M1]*

Theme 1C: ***Parent and ill sibling relationships***

Many participants spoke about the relationship between their parents and their ill sibling. Some well siblings described a tense and estranged relationship between their sibling and their parents:

> *"...well my sister had a horrible relationship with my parents."[FG2F3]*
>
> *"...and her and my Dad would fight all the time to the point where she—when my parents split up she would live at my Mom's house constantly and then they would fight, so she'd move back to my Dad's and she never really had a good relationship with them..."[FG2F3]*
>
> *"...my parents and my sister never—they—they didn't talk, they just argued. So literally like, I'd come home and like, my Mom would be sitting at one end of the table and then my sister would come upstairs and she'd just walk past each other and it would be very—my Mom and my sister really butted heads for about two years they'd have like screaming matches." [FG2M1]*

Despite the presence of poor relationships in several situations, other well siblings described close and caring relationships between their ill sibling and their parents:

> *"And she's really close to my parents, like shares literally everything with my Mom." [FG3F3]*
>
> *"Well I'm—my father has always been keeping a very close eye on her. Like, like she—he'd—every weekend he'd come home from (very distant*

> *country where he works) and then he would—he would actually like, deliberately spend a portion of time with her. Like, taking her out to lunch or dinner to—to observe to see if she's like—if anything's going on with her…" [FG3M2]*
>
> *"…but my parents are very understanding and, um, very close to him, and try and help him through it. And, it's difficult obviously we all know. So, he's lucky we have parents that are really great with him." [FG1F1]*

And yet a few others explained how their parents' skepticism surrounding mental illness translates into an unsupportive environment for their ill sibling:

> *"But, at the same time, it—like, my parents said it could be all in her head, so, they weren't really supportive. Like, with what she was saying." [FG1F4]*
>
> *"Yeah, um, my dad doesn't believe in like mental illness, so, like, um, I've bought him like, you know, like the Dummy books on like, depression. I'm pretty sure he hasn't even open—he hasn't even opened it." [FG1F2]*

Some participants described how their sibling attempted to hide the extent of their mental illness to avoid conflict:

> *"Well my parents were really annoyed and uh, by her actions, and they would get angry at her and yell at her and that—and that made her um, try to hide and so, it wasn't helping anything. Because at one point they thought that she's cured, they'd say, but she would do that when they wouldn't be able to see what she's doing." [FG2F2]*

Theme 1D: *Changes in behaviour of family members over time*

Several participants spoke about how the presence of mental illness resulted in changes in behaviour among family members, the effects on family dynamics, and changes over time:

> *"Um, honestly I—I think what—when I got older I sort of—my brother started opening up to me a little bit…" [FG1M1]*
>
> *"I sort of treated him with a little bit more, maybe, respect. I did it cause I don't know—I think I might have even been irritating growing up so, like, when I came back um, I tried to be a little bit um, nicer towards him and you know, realize that it's actually an issue that needs to be dealt with lightly." [FG1M1]*
>
> *"I'm very close to my sister. Uh, we talk all the time. Like, uh, she's—she's pretty much always there for me when I need her. Uh, it's gotten a lot better in the past six months I'd say." [FG2M1]*
>
> *"Um, and—and I think—like I—especially as we got older, like I—my sister's been more open about things." [FG3F2]*

The process of understanding a formal medical diagnosis as the cause of their siblings' problems gave most participants a better understanding of their siblings' circumstances and allowed them to interact with their sibling in a more positive manner:

> *"Well, in terms of my interactions with my sister, um, I'm definitely more careful with what I say." [FG1F4]*
>
> *"But now, I'm more understanding of the whole circumstances she's going through and that maybe she needs to dedicate more time to this, um, over prioritizing other things that I might think of for myself." [FG1F4]*
>
> *"But, it sort of—the actual official diagnosis sort of led me to uh, maybe communicate with my sister more." [FG1M2]*
>
> *"And, uh, when she saw how we were treating her, then she started to—to isolate herself and whenever she had those thoughts, or that impulses to check she would uh, try to hide or not show that there's something wrong with her. But now we—we've changed. [laughs] Now we know."[FG2F2]*

A few participants also spoke of their attempts to repair estranged relationships with their ill sibling and their uncertainty for the future of the relationship:

> *"…although I knew it wasn't my fault, I did apologize to him for not being there. Even though he probably didn't want me there, didn't even give me a chance to be there, but I—I kind of took ownership of the situation and said okay, like, enough is enough, let's try and improve this. So, we'll see what happens, but we haven't spoken in—in years." [FG2M2]*

While some well siblings spoke of the changes they have personally made over time to improve their relationship with their sibling, others explained positive changes their parents have made to improve family dynamics:

> *"But, now it took time to accept that, okay, this is a real condition that you need to work through it." [FG1F4]*
>
> *"...since then their relationship has totally changed, she's now much closer with my parents. Um, she talks to them like every week, she goes out for dinner with them at least once a month." [FG2F3]*
>
> *"…once when she got diagnosed and started to see a therapist, my Dad completely changed the way that he treated us. It was less—It was less tough love, more like, "oh, how was your day" and stuff. He really started to show that he cared." [FG2F3]*

Despite these positive changes in family dynamics, some well siblings described how their siblings' illness and actions had negatively affected the health and personal growth of other family members:

> *"I feel like this has actually like, like, impacted my—my—my like, second eldest sister in quite a negative way. She just—she—now she's really quiet. I—I—I actually kind of—like, from—from the beginning of my childhood till now, like, I've noticed her just like, not having a lot of self-confidence in herself." [FG3M2]*

Furthermore, most participants described how their family has had to make difficult choices and sacrifices to accommodate for their siblings' illness in order to maintain healthy family dynamics:

> *"Like, even—like, we all know that I'm one of the main triggers for like, lashing out of my sister, so we've even like, started breaking up if we're going on family trips or something. Going separately, which is like, really hard I think for all of us. Like, we all just want to be together and we know that if we are it's not gonna be pleasant." [FG3F4]*

Theme 2: Role of the well sibling

The role of the well sibling in the care and recovery of the ill sibling emerged as a major theme. The extent of involvement in their siblings' care clearly had major implications for the health and well-being of the well sibling. Participants in the present study assumed a wide variety of roles, from little to no involvement in their siblings' care, to acting as the full-time caregiver for their ill sibling (3 of 17 participants). The variation of roles experienced by well siblings is described below. Some participants commented on how their role in their siblings' care affected them emotionally, while others did not.

Theme 2A: *Caregiver*

A few female participants had taken on (at some point) the majority, if not all of the caregiving duties for their ill sibling. In situtations where participants, along with their ill sibling, were living away from their parents, they expressed feeling a lot of pressure to look after their ill sibling:

> *"Well, for three years I was her caregiver. I felt like I was her older sister, I was always taking—like, taking her to and from the hospital, and holding her hair while she threw up, and letting her cry on my shoulder." [FG2F1]*
>
> *"…I'm only two years—two years older than her, so we're pretty close in age—um, felt a lot of pressure to look after her." [FG3F3]*

One participant described how she took on a caregiving role to avoid placing strain on her sister's relationships with her friends since they were both living away from home:

> *"…I tried to make it so that if they were having a problem—because the school was like, on the verge of not letting her come back kind of thing, I—I wanted me to be the middle person between those steps. Between her house mom, between the school, and between her friends…whenever there was something happening like, I would check in and just make sure before the situation progressed—to like, try and deal with it myself." [FG3F3]*

Other participants described caregiving roles that emerged when their sibling had either an estranged relationship with their parents, or one that was not completely honest:

> *"My sister hasn't talked to my mom since that event happened. And then I have my mom like asking me all the time, like "how's your sister?" You know, so, um, I'm very much like, the um person…" [FG1F2]*
>
> *"My parents don't know, because my sister asked me not to tell them. But [crying] I don't know, I talk to—I try to talk to her about it and—and um, make sure that she's not feeling overwhelmed by it." [FG3F3]*

Furthermore, one participant described how she was a pivotal member in her sibling's care by suggesting the need for professional services despite her culture's resistance to seeking care for mental health problems:

> *"And, I was the one who said that maybe we should take her to a—a um, a specialist. And, um, and that's what we did. After a while, though." [FG2F2]*
>
> *"It's just that um, in (home country) it's not so popular to uh, to see a therapist or a psychologist, just in really rare uh, circumstances. And me being the youngest one, that's why I—I took that—that part. I think." [FG2F2]*

Theme 2B: ***Stuck in the middle***

Some participants felt that their role was as a peacekeeper or referee in their family. They described managing the interests of both their sibling and their parents in order to avoid conflict and family drama:

> *"…it's really hard with my Dad because like, he's always the one like complaining that she doesn't do anything and then like, so I'm on the phone with him and he's the one like complaining to me and then I have my sister on the other—like, on the other line and who's like complaining*

> *about him and how he doesn't love her. So it's just um, it's a lot of like, arbitration…" [FG1F2]*
>
> *"…in the two year span when my parents and my sister were constantly arguing, I kind of played the referee and just sort of sat on the fence and sort of if things got too intense I sort of tried to break it up. That sort of thing, like just sort of trying to disperse everyone so that we could come back and talk about it later." [FG2M1]*

Other participants felt that they were stuck in the middle between their sibling and their parents because they were constantly trying to bring their family together as a unit. They described how they tried to engage their ill sibling to encourage them to participate in family activities:

> *"we try to do family outings and like, go skating or something, um, my parents will uh, try to get me to sort of convince him to come out. So, you know, like at three in the afternoon when he's still in bed, um, they want me to sort of like go and talk to him, try to [clears throat]—they think that he'll want to come out if I um, if I tell him to come out. So like, um, that kind of like, sort of like, kind of like being the middle ground to try to like bring them together." [FG1M1]*

One participant described how she tried to encourage her brother to spend more time with her and how she was emotionally affected by the rejection she often experienced by her sibling:

> *"…my Mom kind of asks me for help sometimes. Not in like major ways, but she'll say like, "oh, he's like been by himself for a while, like ask him if you guys can hang out. Ask him if you guys can go see a movie, or watch a movie together." …I mean in that case, I don't mind at all because I like spending time with my brother and it's kind of hard to have him in—like, say no a lot because I really want to spend time with him." [FG3F2]*

Theme 2C: *No Role*

Many participants described having little to no role in their siblings' care because they were unaware of the specifics of their siblings' condition. Often siblings were kept in the dark by their parents, and this limited their ability to support their sibling and their parents:

> *"Like me and her still have a really good relationship, but for the most part I was kept in the dark about the whole thing and I didn't realize how much my parents were having to deal with it." [FG1M2]*
>
> *"So, I wasn't there for the whole process of how she came about reaching out for help, and getting that help, and then the whole process I was just*

> *out of it. So, even now like, I guess it's like, that's the part of her life that I'm not part of really." [FG1F4]*
>
> *"Um, I didn't really get any information from anyone till like, way later on in what was happening. I didn't even know she was going to counseling." [FG2F3]*
>
> *"…I was kind of always the—the third party. They always tried to keep me out of it, cause it wasn't really my place to be in that whole situation." [FG3M1]*

Well siblings described feeling confused about their siblings' illness because they felt their parents were protecting them:

> *"Yeah, exactly, instead of—you know, she wanted to protect us, we just felt in the dark." [FG3F1]*

Some participants described the lack of involvement they had in their siblings' care due to their siblings' reluctance to share the details of their illness with them:

> *"So, in terms of her condition, like, we don't really talk about it, and she doesn't live at home, so, I see her once a month and, it's like—I don't really know how I can help her. She just keeps it to herself…" [FG1F4]*

A well sibling with two siblings with mental illness explained her difference in involvement in her siblings' lives due to her siblings' differing attitudes in reaching out:

> *"…like, I'm not actually that um, informed about what's going on with him because I know like, my sister is really committed to like, reducing stigma and like, that kind of thing so she'll talk about it a lot more, but my brother has always been really introverted and has always never you know, been the one to talk about feelings, so he doesn't really like, tell—like, I don't really know much." [FG3F2]*

In other families, well siblings chose to be less involved in their siblings' life due to an estranged or volatile relationship with their ill sibling:

> *"But, um, once he kinda you know, I guess, had this—this illness, our relationship pretty much turned into—into not much of one at all. So, um, we didn't speak for really a long time unless we were forced to. Um, which didn't happen very frequently." [FG2M2]*
>
> *"So, that was quite difficult living with her because—and I don't really know how to—how to talk to her, or how to understand her properly, or what to say to her because I'm just worried that she might just lash out at me. And, when I mean lash out she actually would loose her temper and—and say some things that were really like, hurtful" [FG3M2]*

> *"But we're not friends because it—like, we can't be friends because he's in not a good place." [FG3F1]*

One participant described her inability to participate in her siblings' care due to the secrecy surrounding her sister's illness:

> *"...and we were told never to bring it up to her though, or never to talk about it with her. Um, and we never have." [FG3F4]*

Some well siblings were unable to take an active role in supporting their sibling for very different reasons. These siblings were either too young to understand, or simply unable to comprehend the details of their siblings' illness:

> *"...like, I didn't really understand what was happening back then and so I kind of played the victim. I thought that she would just like, she hated me, that were just—that I was doing something wrong to her all the time like, her fighting with my parents—they never really got mad at me, so I thought she was the bad guy." [FG2F3]*

Theme 2D: *'Friend'*

Some participants described having a minimal role in their siblings' care, but explained how they remained supportive by maintaining a good relationship with their ill sibling:

> *"Um, but for me, personally, I never really talked to him about it, or I never did anything to, sort of help him through it, other than just be friendly to him." [FG1M1]*

For other well siblings, being a friend to their ill sibling meant checking-in on them periodically to monitor their health:

> *"Uh, but I—we—we speak on the phone and I keep asking her if she's uh, if she has um, aggravated uh—the situation has aggravated now that she's alone and she tells me that maybe not." [FG2F2]*

Furthermore, some participants perceived the 'friend' role as one in which they needed to protect their ill sibling:

> *"Um, when I was in grade eight, my parents sat me down with my sister __ ______ and revealed to me that (his sister) came—came forward to them that her Stepfather sexually abused her. Um, and my first response was being the protective kind of brother that I am, I was like, "well, has anything been done about it? Like, have we contacted police or anything?" And they were like "well, no." And I was—that kind of made me really angry." [FG3M1]*

Theme 3: Positive impact on well sibling

Despite the many negative consequences of their siblings' illness on the participants' lives, all of the participants were able to speak positively about some aspects of their situation. This third theme centers on the personal benefits and positive impact that the participants believed their siblings' illness has had on their own lives.

Theme 3A: *Personal growth*

The majority of participants spoke about how their situation with their sibling encouraged them to become a more supportive individual:

> *"And, in terms of positives, yeah, I agree, I'm a lot more supportive." [FG1F4]*
>
> *"Definitely like um, made me a more supportive person. I think like, uh, growing up it was a—a challenge to sort of, like, what strategy do you take to push him um, to you know, start doing stuff, or do you want to be supportive and understanding? Um, so for me, it—it's definitely just been uh, like when I—I talk to other people about these problems, it's—it's more—I'm more supportive about it…" [FG1M1]*
>
> *"Yeah, and that I had to be supportive about something that I couldn't really understand or I couldn't relate to. But, I knew I had to be supportive." [FG2F2]*

One participant explained how she believes her experience ultimately made her a more supportive person, but how she felt it was difficult to be supportive of others when her brother was really struggling:

> *"But, um, now I feel like I'm a more supportive person, but in the last four years I feel like I was less supportive of a friend, because I was um, feeling a little bit too you know, dragged down with (her brother) that I just didn't even have the energy to support someone else. If they came to me I just kind of felt like I just can't deal with this, I can't—I can't help you right now because it's too much for me to handle. So, I felt less supportive when he was really in his worst stages." [FG1F1]*

Other participants described how their situation encouraged them to be less judgmental of others:

> *"So, I try not to be too judgmental because it happened to me before with my sister and—and I think that's all. That's all, just that I'm being more cautious and trying not to express any judgment…" [FG2F2]*

Furthermore, participants expressed how they were able to grow from their experience in order to become stronger and more mature as individuals:

> *"I definitely like, feel stronger. I feel like looking back um, I mean like, it sucks that it happened but I'm glad because I feel like I'm a better person from that." [FG1F2]*
>
> *"...it really taught me how to grow up, a little bit. Uh, like to sort of—excuse my language but to kick myself in the ass a little bit cause I was—I was always sort of like, unorganized, lazy, that sort of thing, and as soon as that sort of thing started, I sort of just like, had to grow up a little bit and learn to—to deal with those sort of things." [FG2M1]*
>
> *"And um, another positive is I'm probably a lot more responsible as a person to—just to alleviate the stress on my parents." [FG3M2]*

Other well siblings described their personal growth in terms of their ability to be more understanding or sympathetic of individuals with mental illness as a result of their experience with their sibling:

> *"So, I think kind of people have to sympathize with it, I kind of understand that as frustrating as it might be you know, to see someone going through it, it—it's—that's their reality, that's kind of their everyday you know, life. So, I think uh, I think sympathy is definitely something that needs to be you know, shared or considered." [FG2M2]*
>
> *"...it's definitely taught me to be more understanding. Um, like people—everyone has their own kind of thing you know, so just um, accept it and be—or try to work with it." [FG3M1]*
>
> *"I think that it's made me a lot more understanding, or like sympathetic. It's—it—it's hard to actually be sympathetic for my sister because she like, I'm her main target I guess, but just in terms of people with mental illness." [FG3F4]*
>
> *"Yeah, I think that one of the core positives is like, making me a lot more empathetic as a person." [FG3M2]*

One participant described how she became more understanding due to her developed appreciation of the wide range of emotions that individuals can face as a result of mental illness:

> *"...I think that especially for my brother who's bipolar—so it is this like, spectrum of like, highs of lows—I have come away with like, I think a—just a better appreciation of like—like the spectrum of emotions people can feel is incredible." [FG3F1]*

Theme 3B: ***Lessons learned to apply elsewhere***

Many participants spoke about how they were able to draw upon their experience with their sibling in order to help friends or family members with similar problems:

> *"I know at least living with my sister has made it a lot easier to deal with other like, friendships I've had that—where people have come to me looking for help with their own mental illness, so I know that was a really big—not necessarily like, a good thing that came out of it, but, being able to apply what I've learned through living with my Mom and my sister into like, helping like somebody else who might not necessarily have the support at home." [FG1F3]*
>
> *"…I can help with—like my roommate is depressed, my mom has depression, one of my best friends has depression, so you know a lot of people around me—and I feel like yeah, I—I've found a way to help them I think…" [FG1F2]*
>
> *"…just learning how to handle these things that happen in life, I think like you said, can be useful and helping your friends or uh, family if it were—something similar were to happen again or if I ever felt like I was um, becoming depressed or um, anxious, I feel like I could be more aware of it in myself, um, than if I hadn't had these experiences." [FG1F1]*
>
> *"Um, as for like, other relationships, I think it's made me a lot more proactive in terms of like, recognizing mental health issues in the people closest to me. If—so that probably—like, in terms of helping them find help it's been good." [FG1F3]*

One participant explained how his experience with his brother encouraged him to develop a tougher attitude in order to empower others with mental illness to seek help:

> *"But, you know, in situations that were kind of similar I was definitely kind of a fan of the you know, tough love approach. Um, and you—as much as you kind of want to sympathize with—with—with what they're going through, at the same time you're like "you need a kick in the butt here to get kick-started" and sometimes I feel like you know, you need someone to do it for you cause you just can't do it yourself." [FG2M2]*

Participants also described how the difficulties they had faced in their relationship with their sibling had taught them to work harder in their relationships with others:

> *"I think I have become more empathetic, and one thing that I've really learned um, is that you really need to work for relationships. Like, even*

> *when they're your family, it's not just going to fall into your lap." [FG3F1]*

Many participants also used the lessons they learned from their experience with their sibling in order to become involved in reducing the stigma surrounding mental health issues. Some participants described how their individual experience had encouraged them to get involved in mental health promotion at their university:

> *"…like it's gotten me into kind of like, not fighting for mental health, but like trying to get people—other people to understand mental health problems and how it can affect your life. And so like, I'm involved in a club on campus that deals with it and stuff like that." [FG3F2]*

Theme 3C: ***Changed Values***

Many participants felt as though their experience with their ill sibling allowed them to reflect upon their values and to change them in a positive manner:

> *"I think—well, I think in a way it changes your values. Um, you know, like I said before, my situation's a bit different but I think it kind of forces you to you know, kind of figure out what's really important and—and what you—you know, what you truly do value and—and care about. So, you know, whatever the given situation might be it—it kind of forces you to put things in perspective a little bit." [FG2M2]*

The most common experience around values was that of a newfound appreciation for their education:

> *"It's kind of made me more like, dedicated, and hard-working to whatever I throw myself into because like, I saw her fail in high school, I saw her fail in college, and I saw how that kind of brought down her self-esteem and everything and—and how my parents reacted to those failures, and how they weren't necessarily there to push her back up." [FG2F3]*
>
> *"Um, well, I mean I—my brother never—you know, he graduated from CEGEP, never went to university. Um, and kind of I realized okay, you know, the value of education." [FG2M2]*
>
> *"…try to make them feel that um, they have less of their plate by kind of working harder, or achieving more just to—just so they know that, well at least he's doing well." [FG3M2]*

Other commonly cited values inspired by their experiences were honesty, and being true to one's self.

Theme 3D: ***Attention to personal health***

A few well siblings described how their siblings' illness had caused them to focus on their own health and encouraged them to make healthier choices:

> *"I noticed like, um, you know like how I told you about uh, my brother uh, sort of smoking marijuana a lot when he was younger. Um, I actually stopped smoking uh, marijuana all together because I started—sort of started uh, started feeling sympt—what I would perceive how he kind of felt in some ways." [FG1M1]*

Others explained how their siblings' illness offered a distraction from their own problems, and encouraged them to seek treatment in order to be able to offer better support their ill sibling:

> *"...although I do—I identify as being well now, I didn't always. So, around the time that my sister um, became sick I was clinically depressed and she had received a phone call that I was planning on committing suicide. So, um, when I saw that her problems were starting although I didn't really care so much about my life, I did care about my sister so I felt myself take on a lot of responsibility to make myself better so that I could help my sister." [FG2F1]*

Theme 3E: ***Adaptive coping behaviours***

Many participants learned over time to give their ill sibling space in order to preserve the relationship and to alleviate their own stress:

> *"I know when to sort of keep away and sort of just let her have her space. Uh, I learnt that from—after about a year of sort of figuring out what she had." [FG2M1]*
>
> *"...being her younger sibling, especially being the younger brother, I can't exactly always—I can't tell her what to do or, sort of give her—I have to just back away and sort of give her her space." [FG2M1]*
>
> *"...I kind of changed my views about what was happening to her and kind of learned to leave her alone and not entice the—like, if she was getting mad at me, just shrug it off and leave and let her deal with her own stuff." [FG2F3]*
>
> *"...I think the easiest thing for me to do was kinda just take a step back, and uh, and kinda give him his space. I just kinda let him do his own thing..." [FG2M2]*

Some participants were able to use the knowledge gained from their university health and psychology classes in order to cope. They reported an improved understanding of their family situation:

> *"So, especially in like my studies too. Like, a lot of—I was able to apply a lot of the things that like, I learned in my nursing classes to the relationship with—with my sister, which was helpful. Um, in like trying to understand my dad too, why he doesn't understand." [FG1F2]*

Others explained how they made an effort to keep busy in order to distract themselves from their siblings' problems. These participants described spending time away from home and focusing on the now, instead of dwelling on their problems in order to help cope:

> *"...like, I'd go out a lot more. I'd try to like—when—when things are happening at my house especially I don't stay home very often. And if I do, I'm like—I go home for when I need to go home and then I'll like—I'll go to a friends house, I'll go to my girlfriend's. I'll try to find a way to get out. I'll go play hockey with my friends." [FG2M1]*

> *"...I try to kind of shift away from that, and focus on like, the now, like when I'm working out, or at school, or rowing, or whatever sort of other endeavors and kind of just try to push those things to the back. Kind of bring forward what's important, because I see what—I see the toll it's taken on my sisters and my parents. How like worrying about things can really just get in the way of a lot." [FG3M1]*

> *"...my support system was pretty much um, filling up my time with anything like, to do with achieving personal goals, or academic goals, or sports." [FG3M2]*

Theme 4: Negative impact on well sibling

The vast majority of well siblings reported more negative aspects to their experience than positive. This fourth theme focuses on these negative experiences, and the adverse effects experienced by participants due to their siblings' condition.

Theme 4A: *Academic performance*

Those involved in caregiving for their sibling spoke about how this interfered with their schoolwork and had a negative impact on their academics:

> *"My sister was um, hospitalized. It was right during finals, and so I had to like—and it was like a six-hour drive, so we drove six hours. Um, went to see her at the hospital and left the next day for another six hours and like, yes, like it—it was time consuming but it was emotionally consuming. And like, when your sister is hospitalized because like, she's telling you "I just want to die and that's it" and she's sent by ambulance you know, like, it*

> *was um, it—it was really hard. It was hard to like, focus to uh—on school." [FG1F2]*
>
> *"Oh, it definitely affected my school because um, as I said when she would get stressed she would start her cycle of like, throwing up and ending up in the hospital. When she was in school it would be during midterms/finals season, which was the same for me, so instead of studying I would be spending 12-hour days in the hospital, taking care of her." [FG2F1]*

For others the stress encountered as a result of their siblings' illness made it hard to focus on school, and ultimately affected academic success:

> *"Um, I think that the negatives would be um, like I said, just kind of being more stressed at school. I didn't find it specifically interfere with my academics in a certain specific test time or something, but I think overall it was just like, similar things. I can't focus a lot to study um, throughout the past few years, but certain months I guess are worse." [FG1F1]*

Some siblings found that their academics were affected by their choice in coping behaviours. One participant described keeping himself distracted in order to cope with his sister's illness. Unfortunately, his distractions kept him too busy to focus on school and his grades were affected:

> *"Uh, because, I'd become—I'd just try to like push myself to do as much as I could to get it off my mind. So, I'd be doing sports, and clubs, and as much as I could and all of a sudden I was doing like, eight sports, and like, I was doing like four clubs, and like my grades would be dropping, because I didn't have time to do everything." [FG2M1]*

Theme 4B: ***Distress and worry about sibling***

Many participants explained how they were negatively affected by their inability to completely understand what their sibling was going through. This often meant that well siblings felt helpless, as they did not know how they could support their ill sibling:

> *"Right, but I just could not understand how, how to deal with it. I mean, I never saw it coming. So, it was—it was just like a question mark I would say. I was just confused." [FG1F4]*
>
> *"Like, I was really confused because like, I didn't understand what she was like—why she was cutting herself." [FG1F2]*
>
> *"...cause I didn't understand. I just thought my sister was going crazy. [laughs] What was happening, I wasn't really thinking about it." [FG2M1]*

Some participants described how they were constantly worried about their sibling and the possibility that their illness might get worse:

> *"Um, yeah, I mean I guess that's kind of all I think it—it just kind of overall—just worried. I think worried and sad that he was feeling like that and that I couldn't be at home." [FG1F1]*

> *"…but the past two years have been better and she's starting to like her job. But we're worried that this is just a part of her bipolar disorder because she's—she's—at one point she'd be really excited about something, the next thing you know like—like, for example like computer science she'd learn a new programming language in two days. She'd stay up for 48 hours just reading the book because she liked it so much. But then—but then afterwards she'd—she wouldn't—she'd—she'd crash and then she stopped functioning." [FG3M2]*

> *"…but I'm just always—always worried at the back of my mind that like, one day like, if she breaks up with her boyfriend, or—because that's a crucial part of her life right now like, I—I have no idea what's gonna happen to her." [FG3M2]*

> *"…it worried me cause I was always worried like would she be able to you know, live her life cause it's—when she has a major depressive episode it's—she doesn't get out of bed, and she kind of shuts herself off from the world." [FG3F2]*

Theme 4C: *Personal and emotional health*

Many of the participants described how their personal and emotional health was affected by their siblings' illness. One of the most common emotions felt by well siblings was guilt. Many participants felt guilty about their siblings' diagnosis and their inability to help them:

> *"And, I also felt really guilty, because I was like, I was—like, I was—she's my sister, I'm super close to her, I'm supposed to know her and, I'm supposed to pick up on these cues, you know, there's little hints, and, she was asking you know—obviously, she's asking for attention. Not in a bad way, but she wants to know she's obviously hurting, and she needs—she needs help." [FG1F2]*

> *"…I felt a lot of guilt and I think my parents did as well, when we found out." [FG1F1]*

> *"…I have a lot of guilt for not being there for my sister through it all. And, I used to tease her too, a lot, and um, make fun of her for not doing enough. And, like now realizing what she was really going through, and suffering and like, just letting her be on her own when she really needed me." [FG1F4]*

Other participants described a different reason for their guilt. These participants felt guilty for being more successful than their ill sibling, and described how they felt the need to control what they said around their sibling to avoid conflict:

> *"Um, so I think I felt a little bit guilty like, uh, just guilty doing well in things that um, I knew he couldn't do well in things like I could and that made me feel really guilty, and a—a bit more—trying to be a bit more modest." [FG1F1]*
>
> *"Absolutely, yeah. I felt guilty for, like you said, like being successful." [FG1F2]*
>
> *"I find when like, uh—I definitely understand that, the whole like guilt thing. And like, when I go home it's—I kind of have to like—if my brother's around I have to sort of like, uh, control what I'm saying just so I'm not—so I don't you know, end up bragging about like—accidently bragging about you know, my grades, or stuff that I'm doing uh, in school." [FG1M1]*

Another common feeling that participants shared was fear. Many participants spoke about how mental illness ran in their families, and how the presence of their siblings' illness caused them to fear that they too might one day develop a mental illness:

> *"...I was like, 10, when my mom really had almost—not necessarily a nervous breakdown, but she was having a really hard time and I remember very vividly her being hospitalized and all this stuff and it was when I became aware that my sister was also like—and going down not the same path but similar—similar state. So, I remember being absolutely terrified, one, that it would happen to me, and two, that the rest of my life was going to be like that." [FG1F3]*
>
> *"For me, uh, I'm afraid that I might at one point get this condition as well, or something else because she developed it out of nowhere." [FG2F2]*
>
> *"But my—like bipolar does run in my family. Um, and like, my Dad has a couple siblings that are bipolar and one of my cousins is, and so my cousin who is bipolar just got married and now she's thinking of having kids, so it has been a family discussion like, if you have kids there is the possibility that they'll be bipolar..." [FG3F1]*

In addition, many participants spoke about the added stress overall:

> *"...I don't know in terms of—it's actually like—I found it really hard having to like, manage like, school and my life and then her life too. Because like, not many people were actually like present and helping her out, so I felt like a lot of the weight was on my shoulders." [FG1F2]*

> *"And then, I—then he started drinking—it just kind of continually got worse and worse, and, I mean, I was just stressed all the time, at school. Um, I just kind of had this like, constant like you said, weight on your shoulders—it wasn't really like I was like um, the primary caregiver but it—I just felt like I didn't want to be away from home." [FG1F1]*
>
> *"…the biggest thing for me was just trying not to burden my parents. So, I would take a lot of stress and just like, keep it on myself." [FG1M2]*

Some participants explained how their experience with their siblings' illness had changed their personality. These well siblings described becoming more introverted and closed off as a result of their siblings' illness:

> *"I think the way that it's affected me is that I've kind of become more introverted because of it because I don't want to ever have any suspicions—not suspicions, but being worried about me and that—that kind of affected me. So, everything that's happened—not to say I'm an emotional person, but when I do kind of have something going on, I try not to express it so hard and try not to make such a big deal of it because I don't want her to worry." [FG3M1]*

One participant mentioned how his siblings' illness encouraged him to engage in negative coping behaviours. This participant explained how he turned to substance abuse as a coping mechanism to avoid being at home with his sister:

> *"...you know, I—I—for a while I started just you know, on weekends instead of just going and doing homework, I'd go and smoke pot with my friends." [FG2M1]*

Other commonly mentioned negative effects on personal and emotional health included the development of trust issues, frustration with family and friends, and difficulty sleeping.

Theme 4D: *Deteroriation of relationships with family and friends*

Many participants spoke about how their relationship with their ill sibling deteriorated due to the resentment they developed for their sibling:

> *"But, once we lived together it um—it ended up deteriorating because before we had never been close because she was always a little bit self-absorbed and I noticed that as she was sick she was still that way, because I was constantly there for her problems but she never um, returned the favor." [FG2F1]*
>
> *"In terms of friendships, it didn't really change mine, it just made me resent her a lot and like, whenever I would have friends over, I would tell them how much I hated her and how much she hated me." [FG2F3]*

> *"The downside is that now I still have a little bit of resentment towards her because now she's done better and she's been better for a while, but any kind of minor achievement she does is completely blown up in my family's eyes." [FG2F3]*

> *"I definitely agree with that, in that like, a lot of resentment builds up because I feel like my—I'm very close with my sister and same with my family. Like that definitely hasn't degraded my relationship at all, but they definitely hold her to a different set of standards than they hold me." [FG3F3]*

Other participants described a loss and lack of connectedness with their ill sibling:

> *"And so my relationship with him totally deteriorated, which was awful and even looking back on it now—like he was diagnosed like seven years ago or something, and I just visited him where he's living on this past Sunday. And still, I think that my relationship is so superficial, because I kind of have lost about seven years of my relationship with him…" [FG3F1]*

> *"Um, yeah, just on like the like, superficial relationship kind of lost sibling, I—I feel that a lot." [FG3F4]*

> *"So, in terms of superficial relationships, um, when I'm around my sister I always have to watch—like, watch what I say to make sure that she doesn't—that it's appropriate, or that it's—it's not damaging her self-esteem in any way." [FG3M2]*

Many participants also spoke about how their relationship with their parents had deteriorated as a result of their siblings' illness. These well siblings described feeling as though their parents favor their ill sibling:

> *"…my parents would always just like, be on her side of fights and—and tell me and my other sister to be nicer to her and it never made sense to me, just—like it felt like they favored her and she was just not nice." [FG3F4]*

> *"…but at the same time—and I know that it's like, probably immature and selfish of me, but I just feel like, everything how my parents just favor like—well, I don't know if favor's the right word, but they're—they take her side and they tell us to be nicer to her and—and—and she's always right and everything, kind of like, builds up resentment from me like, towards my parents." [FG3F4]*

Similarly, many participants described how their relationship with their parents had deteriorated because they felt as though their parents were paying too much attention to their ill sibling, and not enough attention to them:

> *"…when I was like going through high school and stuff, she'd be—she paid so much attention to him, and to his needs because he wasn't in a*

> *good place and I still didn't really understand that he needed all that extra support…" [FG3F1]*
>
> *"…it made my parents miss out on a lot of important moments in my life, they missed my high school graduation because she was in the hospital, they missed—they just didn't notice when things were wrong with me because they were constantly taking care of her." [FG2F1]*

One participant even explains how her relationship with her parents was negatively affected because of the negative interactions she witnessed between her father and her sibling:

> *"…she kind of re—changed my relationship with my father, cause he and her would have like, screaming matches. To the point where he would make her like, burst into tears and leave the house for like, the night or the day. So, I became really afraid of him…" [FG2F3]*

In addition to the deterioration of relationships with the participants' ill siblings and their parents, many participants spoke about how their relationships with their friends were negatively affected as a result of their siblings' illness:

> *"…because of her relationship was uh—and the—the trust issues that she developed afterwards was—it sort of rubbed off on me and like, for the first little while like, I had—I had a lot of trouble uh, developing trust for people." [FG2M1]*
>
> *"…but as he was—so he was living at our house all throughout high school and so pretty much from high school on, I just never wanted to have any friends over…" [FG3F1]*
>
> *"I try not to draw a conclusion on anything or on anyone until I have a series of—points of evidence. Um, so I—that really pisses off one of my friends [laughs] cause they—cause they—cause they—they would—they—a couple of my friends are really close where they would like pour their feelings onto me and then I just kind of like, well, it's not really that big of a deal." [FG3M1]*

Theme 5: Information, support, and professional services

Participants spoke about the information and support that they received and sought out, as well as their interactions with professionals. This theme focuses on the support and information that well siblings received and how they went about finding this help, as well as their interactions with healthcare professionals, including their impressions of the quality of care that their sibling received.

Theme 5A: *Support and information seeking behaviour*

A few participants spoke about seeking professional support for themselves, from a therapist or psychologist. These participants explained how they found this to be beneficial in relieving some of the stress caused by their siblings' illness:

> *"I've been seeing a therapist too since um, I was about nine years old cause my parents split and stuff. So like, I could—like I sought help again um, from someone and um, that made me feel better to be able to have support…" [FG1F2]*
>
> *"I've seen not (university in Canada) uh, mental health but uh, (university in Canada) counseling. And, I had a really good session. Just one time. And, it was very good." [FG1M2]*
>
> *"...I saw a psychologist because I was worried that like, you know, feeling—I was feeling depressed and stuff. Um, and so that was like my first instance of even like, talking about my brother. I'm like "my brother is like, bipolar." And that was the first time I had told anyone. Um, so yeah, I think that was a very good process…" [FG3F1]*

Although some participants did seek out professional support, many found the support offered through their family and friends to be sufficient:

> *"…well I talked about it with my Mom because my Mom had talked to my sister's therapist who had told her you know, like, what was going on." [FG1F2]*
>
> *"…as far as support it was entirely through my parents. Um, and that—I felt that was enough just cuz they're—they're very there for me, as well as being there for my sister the whole time." [FG1M2]*
>
> *"I think what my like, my mom asked me to do was to be really open with her, and like, she would rather know everything about all of the stresses I'm having than be in the dark, even if it you know, like, stresses her out. Like, she specifically asks me to tell her, so I've become like, really open with her…" [FG3F2]*
>
> *"…but—but up until last year I realized that the best idea would be to—uh, for me anyways—is to uh, speak to someone about it, and really let them understand how you're feeling. To really let them know like, what you're—trying to make them understand what you're going through. And I feel that that puts a lot of stress off my back." [FG3M2]*

A few participants commented on how they had very little, if any, support, and how difficult this made it for them to understand their siblings' diagnosis:

> *"There also really wasn't any support, I didn't know what was happening…" [FG2F3]*

> *"I didn't really get much support even though I went to the hospital with her all the time. Um, the doctors didn't really give me any information per se, or tell me what I was supposed to do." [FG2F1]*

Many other participants commented on how their siblings' illness made them less likely to seek support for themselves because they felt their problems were minor in comparison to their siblings':

> *"...I'd probably be less likely to seek help because uh, just seeing how severe his problems are and you know, comparing them to any problems I'm having at the time, I just wouldn't really take them that seriously that I should sort of go seek the kind of help that he's getting." [FG1M1]*
>
> *"...I'm sort of one of those people that if I have something wrong, if something's bothering me like I won't tell people. I'll just sort of like, stick—stick it myself and like, I'll just sort of deal with it." [FG2M1]*
>
> *"....I haven't had much experience talking about my own problems and to me it's—how could I phrase this—but, I think there are a lot more things to worry about than my like, miniscule, minute problems." [FG3M1]*
>
> *"... I've never actually done anything, and I also think part of it is like, I'll just think and I'll think about my sister and say like, oh people like her need—need the help more than I do anyways." [FG3F4]*

Although some participants found that their siblings' illness made them less likely to seek support, many others found that their siblings' illness had actually encouraged them to seek support in the future if they thought they needed it:

> *"But, seeing them being strong enough to go and like, get help for themselves has definitely made an impression on me that like, it is okay and it's a reaffirmation that it's—it will get better if you want it to." [FG1F3]*
>
> *"I would say I would be more likely to go get help. Just cause um, like my sister sees a therapist once a week, and I do see improvements. So, it does help to have someone that you can talk to outside of your I guess, personal environment." [FG1F4]*
>
> *"I think—I think more um, I actually like wish that I had sought—like got help when I was thinking about it. Um, yeah, I think just, knowing that—knowing that it's just uh, someone to talk to um, and seeing how it has like, gotten better because of that." [FG1F1]*

For those that did look for information about their siblings' illness, the Internet was a common resource, as well as textbooks from related university courses:

> *"I guess like, I received um, I had one class that was about um, um, like, stressors of life and basically we had a guest speaker about—who came*

> *and talked about um, bipolar disorder and um, his episodes of depression and mania…" [FG1F2]*
>
> *"So, um, and otherwise, um, with different things like once he started drinking and alcoholism, I—I didn't really like look—get any like information other than looking stuff up online." [FG1F1]*
>
> *"I looked a lot through like, my textbooks and learned a lot about her con—her condition is kind of special case, but I mean, I learned what I could from textbooks." [FG2F1]*
>
> *"Yeah, I've looked on the web before the actual treatment, and during the treatment and after, even—even now." [FG2F2]*
>
> *"…I found myself doing a lot of like, research on Wikipedia and—and stuff like that, but I still—I still wish that I had and that I do know more about my sister's specific conditions and—and her specific like, uh, medications, or therapy sessions, or anything. [FG3F4]*

One participant explained how she got involved in a club on campus to reduce the stigma surrounding mental illness, and in doing so, ultimately increased her own knowledge of mental illness:

> *"…we're having like a speaker series, uh, where each time we have a different topic related to mental health and—and I've actually like—through organizing these events and also you know, obviously attending them, I've been learning a lot." [FG3F2]*

Another participant described how he used the acquisition of knowledge as a support tool. He explained that by learning more about the things that were upsetting him, he was able to feel less stressed and better supported:

> *"Like, that's it—that's how—that was my way of getting over it, and that's kind of what I've used to now. Like, since then to kind of get over things—like it's kind of cliché, like learn about your problems. Like no, like actually do it. [laughs] Education—educating yourself about something will almost every time help." [FG3M1]*

Theme 5B: ***Interactions with healthcare professionals***

Very few participants interacted with healthcare professionals directly. Those who had interacted with healthcare professionals commented on these interactions and whether or not they thought the professionals were supportive. Some participants had excellent experiences working with professionals:

> *"Yeah um, it wasn't even—it wasn't necessarily my sister but um, one of my good friends had a really serious bout of depression last year and I ended up—I found out she was participating in self harm, so I ended up*

> *going to the school counselor and like, letting her know and the school took care of everything. They called her parents, they told her parents and gave them all the information to get her into counseling and into like, the doctor to get a prescription for anti-depressants and everything. So they were really good about that." [FG1F3]*

Other participants had less positive experiences where professionals were less helpful. One participant explained that although she was supported by a professional, she felt that the care was focused on how to support her ill sibling, and did not include consideration of how she was coping with her sister's illness:

> *"…but for me whenever I saw—like when they would make me—the school would make me like, talk about it, it wasn't um, how I was feeling or how I was reacting, it was how I should approach my sister. Yeah. And like how to offer support, how I should talk to her, like, what kind of things—like, what kind of language to use." [FG3F3]*

One participant who had had many interactions with healthcare professionals commented on how she found these interactions to be very inconsistent. She had been involved in both excellent care, as well as less than adequate care:

> *"I think I've just been really frustrated with the way—I've seen both really good care, and really, really poor care…Um, there's been issues where doctors don't even recognize it as a actual like, issue and they're—to the point where somebody is causing lots of self-harm and contemplating suicide quite regularly and the—the doct—the physician is "oh well, uh, you—talk to your parents. Talk to your parents about it, and it will totally be fine." And, sometimes the parents aren't even supportive." [FG1F3]*

Theme 5C: ***Perceptions of quality of care***

Many participants commented on the care that their sibling had received, and the quality of this care. In many situations where the ill sibling had changing diagnoses over time, participants' perceptions of the quality of care was very poor:

> *"So, I was living at home with her and, she was uh, switching between therapists and different doctors, and her diagnosis kinda got changed a whole bunch. And, so they were having her on different medications all the time, and different types of treatment." [FG1M2]*
>
> *"…just seeing my sister sort of switch from therapist to therapist, I thought there was a lot of mistakes made in that process, where diagnosis kept changing and different approaches were—kept being taken." [FG1M2]*

Some thought that the care their sibling had received was poor due to policy or systems-level issues, such as lack of standardized diagnoses, or the inability to share files:

> *"There's—I feel like there's no standardized like, this is how we deal with these situations in order to help people get better. It's very much up to the professionals like, whims, almost." [FG1F3]*
>
> *"So, I'm not sure how much information could be shared, but it seemed like everytime she was starting new, and then everytime it was something different and I think that was maybe an artifact of the fact that it was just different people, different backgrounds." [FG1M2]*

Despite the dissatisfaction with care that many participants experienced, some participants spoke about the excellent care their sibling was receiving and how this was helping their sibling to recover:

> *"Like, more controlled because he's having—like, it's a mental wellness community, so he has like, lots of therapists and like, all that kind of stuff. So, he seems like he's in a better place…" [FG3F1]*
>
> *"…and—and then after that like she—she started getting help, she started going on some medication and seeing therapists and uh, it started helping a bit." [FG3F2]*
>
> *"So, she's at—uh, it's like the size of a large high school, so she gets a lot of support there and like, she gets um, a lot of accommodations in her school—like, tests and stuff like that which really helps to like, reduce her anxiety." [FG3F2]*

Theme 6: Advice to others

Each of the focus groups ended with an opportunity for the participants to share their advice to other well siblings, to other family members, and to healthcare professionals. The majority of advice that was offered was directed towards parents and other family members.

Theme 6A: *Advice to other well siblings*

Participants who had found their support systems to be helpful suggested that other well siblings should welcome support into their own lives:

> *"I would say uh, like, definitely welcome support. Um, when I was sort of—I haven't really looked for anything and I think that sort of this idea that I don't really need support, or I shouldn't be going to support unless its like, super serious, has been part of the reason why like, I've had*

> *problems with drinking in the past. Um, so maybe just be—be more open to support." [FG1M1]*
>
> *"...well I guess my advice to other siblings would probably be just like, find—find someone to talk to. Find something to do to like, keep your mind off of it, but don't like don't uh, like really find—uh, I didn't have someone to talk to and that's why I sort of fell into like, the wrong crowd and started like smoking and drinking and doing sort of like, rebelling that sort of thing." [FG2M1]*

In addition, those participants who were acting as caregivers for their ill sibling suggested the importance of distracting yourself and taking care of yourself to avoid becoming overburdened:

> *"I would say surround yourself. Honestly, like if you want to be able to help others you have to be healthy and you have to take care of yourself. It's either like with friends, or family, or like, a therapist or, you know, just like do things for yourself because like if you're not in shape to helping others, you're just going to destroy yourself and just drain yourself." [FG1F2]*
>
> *"I would say to well siblings I would say although you should be supportive, it's not completely your responsibility on your own and you should um, you should use resources to help so that you're not alone with this responsibility of taking care of someone um, when it's not really—not that it's not your problem, it's just like, it's a burden on you to be the only person responsible." [FG2F1]*

Participants also spoke about the importance of taking time away from their ill sibling and "stepping back" in order to gain perspective on the situation and offer better support to their ill sibling:

> *"I think uh, being able to detach yourself from the situation and to try to look at the big picture of what's happening, is also really important." [FG3M2]*
>
> *"So I think like you—stepping back, taking a step back—I mean you can't really be like "I'm gonna move out" but [laughs] it definitely—it's like, distance." [FG3F3]*

Many well siblings advised other young adults in their situation to be patient, as increased understanding comes with time, making things easier:

> *"...just for, kind of more, perso—personal thing is just really be patient. I think it's a difficult part." [FG1F1]*
>
> *"I know my youngest sister is now around the age that I was that I was really having a hard time dealing with all the stuff going on in my family, and I think more for her than anything else is just like reassurance that*

> *she's going to be able to get through, and that eventually she will be able to understand a lot more of what's going on." [FG1F3]*

Maintaining a close and open relationship with the ill sibling was also advised:

> *"I guess maybe just to stay in close contact with your sibling, if possible." [FG1M2]*
>
> *"I would say like, just creating an open dialogue also between you and your siblings and—and it is really helpful, and knowing what's going on is nice." [FG3F2]*
>
> *"...I wish that I had um, behaved this way with my brother, but um, kind of understanding that even if—even if you're sibling is in like, a volatile situation, or like, really not in the best place, um, you're not gonna break them. Especially if you extend like, a lifeline. Um, lifelines never break anyone." [FG3F1]*

Theme 6B: ***Advice to parents***

The most common piece of advice that participants had for parents was to be more open and honest with their well child or children, and to help them better understand the situation so that they don't feel left in the dark:

> *"Maybe kind of explain to me what was happening and why she was acting the way she was." [FG2F3]*
>
> *"Like, really talk to the kid, like the other kids and make sure that they—they like, they understand how they feel because like uh, and—and it's not easy to do either because they're so caught up in whether their child might be—might be behaving that it's not an easy thing. But like, just the realization that it's not always just—it's not just affecting them or not just affecting that child. It's also affecting the other uh, people in the family." [FG2M1]*
>
> *"I think that they should have been open and honest about my sister, and I think also, kind of how they—how they keep it so quiet like adds to the stigma of that it's a bad thing or something to hide, which it shouldn't be. So I think that there should have been a lot more just openness and—or family discussions about it." [FG3F4]*

One participant noted that she would have appreciated more honesty from her parents so that she could have been able to offer them help in supporting her ill brother:

> *"So it—I think especially in the beginning if let's say my parents had you know, talked to me about that, or maybe like, included me in a discussion, maybe with a therapist or someone to say like, these are the things you can do. Like, it's not much but it's—at least you have been told or have been taught like how to deal with it a little bit." [FG3F2]*

Participants often felt as though their parents did not fully acknowledge mental illness as a real problem. In these cases, the participants advised other parents to become better informed in order to recognize the illness and to be more understanding:

> *"Well, for me my Dad is really not understanding so, to tell him to like, try to understand or at least you know, like, he's—I don't know, to him it's just an excuse for not doing the dishes, or not working, you know, and it's just—he doesn't—he doesn't even try to understand. So, for me you'd be like "try to be open-minded and try to like put yourself in her shoes and just see what she's feeling."" [FG1F2]*
>
> *"So, my advice would just be whether or not you agree with you know, the—your uh, daughter, sibling's uh, standpoint uh, just be supportive no matter what." [FG1M2]*
>
> *"...I think parents should acknowledge the fact that it is an actual illness, and it shouldn't just be overlooked..." [FG1F4]*

Some of the well siblings described feeling like they missed out on quality time with their parents as they were spending all of their time with the ill child. These participants suggested that parents remember to spend time with their well children as well:

> *"And as for parents, I would say that they definitely need to take into account if they have more than one child that um, they shouldn't spend all their time and energy helping the sick one. I guess they might need a little bit more time, but the well child needs time for themselves as well." [FG2F1]*

Some participants worried about their parents' health, and wanted to remind them to take time for themselves and to ask for help when needed:

> *"...kind of going off again, I think for my parents they were great, really supportive, but I think seeing um, I think my advice would just be to remember to take care of themselves. Um, I saw them a few times really start fighting and um, getting really bad just because they—they were taking on too much stress from him and um, just weren't healthy with their relationship with each other, or just healthy physically and emotionally with themselves." [FG1F1]*

For those well siblings who had developed resentment towards their parents and siblings due to a perceived parental favoritism for the ill sibling, more discipline of the ill sibling was encouraged:

> *"...I also just think that—that like during fights—I—I don't know though, because I don't—I don't know. Like, my sister is sick, but she also just*

> *sometimes says things or does things that aren't acceptable and—and—and in my mind like, even though she's sick sometimes you should say like, "you shouldn't do that." But my parents won't even remotely discipline her, so I—I think that sometimes like, telling her what she's doing is wrong could help her so she knows." [FG3F4]*

Theme 6C: ***Advice to professionals (healtchare providers and policy makers)***

Participants offered many pieces of advice to professionals working with families with mentally ill siblings. Many participants noted the importance of offering support to all family members, and not simply the ill sibling:

> *"I guess like, also offering support for others. Like, I'm in-doing this—this—my clinical, like we're in um, external clinic at the (local hospital), and you know, like we offer support for parents too, you know. So like, I think uh, like uh, healthcare professionals also um, look after the caregivers around um, the clients they interact with." [FG1F2]*
>
> *"I would probably say not necessarily just with well siblings but to talk to anyone who's in their household, probably taking care of them when these problems are happening because my sister was of age when she started developing problems, so I think the healthcare professional didn't really see fit to explain to me necessarily what was going on. But, I was the one that had to be there for her and I wasn't really sure what I should be doing for her…" [FG2F1]*

Many participants also spoke specifically about how they would have appreciated group sessions where they could have interacted with a healthcare professional and their entire family:

> *"…maybe it would have been nice to have some group sessions or at least me and her so I kind of realized what was going on, instead of spending so many years hating her for something that wasn't necessarily her fault." [FG2F3]*
>
> *"…so I—I guess that's probably one of the things I really would have wanted, was just a group session with the rest of my family to understand, cause I have a younger sister too and that was—that was very, very, very tough for her. She didn't understand and I—I had to be the one to sort of explain it. Uh, so, I guess like a session to let everyone understand and everyone sort of talk out what's going on uh, would have been beneficial." [FG2M1]*

In reference to policy makers, many participants felt that it was important that mental illness become a top priority in order to reduce the stigma surrounding it:

> *"I think there's a big stigma around it still. You know, like, even though like, it's becoming more known, I think there's so many people you know,*

> *like it's a lot easier to have like, hypertension or like a physical illness, whereas like, when it's your mind, then it could just be like, how do you distinguish between like, an actual illness and just like, a bad tendency or a bad habit." [FG1F2]*

Comments on Group Interaction and Participation

Although not a major theme, there was some group interaction between participants, but these interactions were only minimal despite prompts by the facilitators to ask groups to reflect on how each participants' story was similar or different. Some participants reflected on why the focus group process was interesting for them, and related their experience to their fellow participants:

> *"I think it was interesting to hear what everyone else had to say. I think we've had like all different—very different experiences. It was really great to see that we still did have like common points though like even though our stories were different." [FG1F2]*

Each focus group also ended with a question asking the participants about why they had chosen to participate, and whether or not they had enjoyed the experience. Many participants explained that they had chosen to participate because of the opportunity to talk about their own experience, which they were not always able to share freely:

> *"Very similar, just wanting to have an opportunity to talk about it, hear other people's stories because I think we hear a lot about how the actual person is affected with this mental illness but not so much their support network, how they've actually been affected." [FG1F1]*
>
> *"Definitely interesting cause I—I don't really tell people about my experience with it as much. And I guess it's not something that's really brought up as much, especially because there is always so much that hasn't been talked about, I guess with mental health in general." [FG3F2]*

Others wanted to participate in order to hear from other well siblings, and to compare how their stories were similar and different:

> *"Um, yeah, I was also uh, very interested in learning more about it, hearing other people's stories." [FG1M1]*

One participant explained that she had enjoyed the focus group experience, and found the group environment to be more comforting than an individual interview:

> *"Um, I liked it. I feel like I would have felt really awkward in a one-one-one session. It's also a bit comforting, even thought it's kind of morbid that everyone else is kind of going through something. You're not the only*

one. It’s uh, I don’t know. It’s nice to hear that other people can come out of it too and yeah.” [FG2F3]

Discussion:

In families where members suffer from mental illness, research has traditionally centered upon the patient, or the primary caregiver of that patient. Studying the impact of familial mental illness on well siblings is a relatively new field, with few studies providing firsthand knowledge from well siblings themselves. The findings from this thesis contribute to our understanding of the experiences of well siblings, and their needs for information and support.

This discussion is divided into sections in order to further explore the major results presented above. It begins with a reflection on the overall findings, then examines the contributions to new knowledge, and finally discusses the implications the results have for healthcare delivery. The results of this thesis will be discussed in the context of existing literature on the subject, indicating where the current findings contribute to existing knowledge, and where these results are in agreement or disagreement with the current literature. The discussion section will end with an overview of the limitations of this study, and directions for future research.

Reflections on Overall Findings

Prior to addressing the content of the focus groups, it is important to note the unexpectedly high and rapid response rate to this thesis study recruitment. For the purposes of this study, 2-3 focus groups with 5-6 participants in each group were planned. Not only were we able to conduct 3 focus groups, with a total of 17 participants, but an additional 15 participants were also placed on a waiting list in the event that a spot in one of the focus groups opened up. Due to the scope of this study and the time constraints surrounding a Master's thesis, we were unable to hold additional focus groups, but it is clear from the response rate that a total of five focus groups would have been possible. Supportive services offered to patients and families typically overlook well siblings (Sin et al., 2008), leaving well siblings confused about the details of their siblings' condition and without a place to turn for support. Participants in the focus groups described keeping their stress bundled up, as they did not want to overburden their parents. This is consistent with findings in the literature that indicate that siblings desire an opportunity to discuss their experiences and how their siblings' illness affects them personally, but find it difficult to find such opportunities (Sin et al., 2008). Thus, it is perhaps not surprising that the response rate was so high. The focus groups conducted for this study provided participants with such an opportunity to speak about their experiences in a supportive environment with individuals who had similar experiences.

In addition to the high recruitment response rate, the majority of those participants who responded to recruitment ads found these ads through methods of e-communication. 12 of the 17 participants (71%) indicated that they had learned of the study through e-mail or social network ads. This result is not surprising given the age range of participants recruited for this study. The predominant users of social networking sites are young adults; 75% of Internet users under the age of 25 have a profile on a social networking site (Correa, Hinsley, & de Zúñiga, 2010). Given that participants for this study were young adults, the author chose to target the majority of her recruitment efforts to e-communication. The success of this strategy is likely due to the fact that university students are said to spend anywhere from 30 minutes to three hours a day on social media sites (Correa et al., 2010).

Although the facilitators used prompts to encourage the participants to compare their individual narratives there was very little group interaction. Instead, participants spent the majority of the focus group session discussing their own experience. When reflecting upon the focus group process, many participants discussed how they had enjoyed the opportunity to discuss their story, especially considering that the focus was often on their ill sibling, and not how the illness affected other family members, like themselves. Given that well siblings find it difficult to find supportive outlets to discuss their experiences (Sin et al., 2008), it is not surprising that participants enjoyed the opportunity to share their story, and preferred to focus on their own narrative as opposed to comparing their story to the other participants' in the focus group.

The results of these focus groups indicated a mix of positive and negative experiences for the majority of participants as well siblings. This is consistent with the existing literature, with some sources citing mainly negative experiences (Cohen, 1999; Hastings, 2007; Loukissa, 1995; McKeever, 1983; Sanders & Szymanski, 2012), and others citing mainly positive experiences (Schuntermann, 2007; Sin et al., 2008). Although participants spoke at length about the negative experiences they encountered, many found ways to express the positive aspects of fundamentally negative experiences. In the literature, resilient siblings are portrayed as those who are able to identify the positive aspects of an overall negative experience (Barlow & Ellard, 2006; Sharpe & Rossiter, 2002; Sin et al., 2008; Tsao, Davenport, & Schmiege, 2012). Due to the presence of both positive and negative experiences among siblings, this discussion section will now present these positive and negative aspects separately in further detail.

Positive Experiences of Well Siblings

Many participants found their overall experience with their ill sibling to contain some positive aspects, primarily an opportunity for personal growth and improved family dynamics. Current literature suggests that the most successful families are those who display effective communication skills (Krysan et al., 1990). This is consistent with the advice that participants offered to parents where communication could have been better. Participants suggested that open lines of communication and honesty from parents regarding their siblings' illness fostered the most positive experiences, and enabled participants to become part of their siblings' support system. The importance placed on honesty and involvement in their siblings' care is consistent with the finding that those well individuals who are more involved in their siblings' care have a greater number of positive outcomes (Schuntermann, 2007). Many participants also discussed the close relationships that had developed with their ill sibling and their parents as a result of their siblings' illness. These participants described how they believed these close relationships might not have developed if their sibling had not suffered from a mental illness. This finding is consistent with evidence that states that many well siblings experience an improvement in family dynamics over time and the development of a family environment that is cohesive and resilient (Sin et al., 2008). Other studies have demonstrated that the presence of a hardship such as mental illness, can actually improve sibling relations and encourage a closer sibling bond (Sharpe & Rossiter, 2002).

The majority of participants also spoke about how their siblings' illness had offered them an opportunity for positive personal growth. These well siblings discussed how their experience had given them an opportunity to become a more supportive individual. In some cases, this quality of becoming more supportive translated into participants feeling as though their experience had given them an opportunity for personal development, and a chance to support or help others around them going through a similar experience. There is evidence to support this finding in that the presence of familial mental illness often encourages well siblings to become more supportive, caring, and mature individuals (Barlow & Ellard, 2006). Finally, the majority of participants also spoke about how their experience had contributed to their development as more understanding and sympathetic individuals. These well siblings described how they had become more accepting of those diagnosed with mental illness, and how they believed their siblings' illness had taught them to be less judgmental of others. Again, this is consistent with other findings (Sin et al., 2008).

Negative Experiences of Well Siblings

Despite the positive impacts described above, the overall experience appeared to be more negative than positive. Participants in the focus groups described their confusion with their role in their siblings' life. Many participants explained how they wanted to offer support to their sibling, but due to their lack of knowledge surrounding their siblings' condition were unable to do so. This finding is consistent with literature that states that well siblings often experience confusion regarding the details of their siblings' condition (Stålberg et al., 2004). In addition, many participants described feeling as though their parents' intention was to shelter them from the harsh realities of mental illness, but this simply left the participants feeling like they were being kept in the dark. The literature supports this finding, explaining that parents often try to shelter their children, and therefore provide inadequate information about their ill child’s diagnosis. This leaves well siblings feeling confused about what their ill sibling is experiencing (McKeever, 1983).

The majority of participants discussed how their siblings’ illness had caused them increased stress in their life at one time or another, with some reporting outcomes with respect to negative academic performance. These well siblings described how the stress and other emotions they experienced as result of their siblings’ illness made it difficult for them to focus on school, and affected their academic achievements. This finding is consistent with literature that states that well siblings experience a variety of school-related issues due to their siblings’ illness, including absenteeism, anxiety, stress, and lack of confidence (Barlow & Ellard, 2006). In addition, many participants described feeling distressed or worried about their siblings’ health, due to a lack of understanding of the extent of their siblings’ illness. This is consistent with previous research that states that well siblings often worry about their ill siblings’ health, and as result become emotionally engaged in their siblings’ everyday life in order to stay abreast of any new developments in their mental health status (Stålberg et al., 2004).

All of the participants expressed experiencing some sort of negative effect on their physical and emotional health as a result of their siblings’ illness. The most common negative effect experienced was guilt. Many participants described feeling guilty about being more successful than their sibling, and feeling as though they had to censor themselves around their sibling to avoid making them feel less accomplished. Other studies have found that mental illness can often result in different abilities among siblings, promoting rivalry between the siblings and a sentiment of guilt among the well sibling (Stålberg et al., 2004). Many participants experienced guilt when their sibling was first diagnosed. They described feeling helpless and feeling as though they had failed their sibling because they were unable to recognize the mental illness or cure them. Research shows that well siblings often experience a feeling of guilt for being healthy, when their sibling is suffering from the difficulties associated with mental illness

(Stålberg et al., 2004). In addition, a few participants spoke about fear, mostly afraid that they too might develop a mental illness in the future. Although some participants had a family history of mental illness, and others did not, there was a common expression of fear. The literature supports this sentiment of fear, finding that well siblings often perceive themselves to be at higher risk of mental illness than the general public due to their siblings' condition (Sin et al., 2008). A few participants described how their siblings' illness had affected their physical health. Some had turned to substance abuse in order to cope with the stress, a finding strongly supported by the literature, which states that well siblings are at an increased risk for 'acting out' and developing behavioral issues (Hastings, 2007).

Many participants also spoke about how their experience caused their relationships with family members and friends to deteriorate and the resentment they felt. This finding is supported by the literature, which describes that well siblings display resentment towards their ill sibling for receiving more attention and praise from their parents than they do (Sin et al., 2008). A number of participants also described the deterioration of their relationship with their sibling, some reporting that they felt as though they had lost their sibling. Many sources support this finding, stating that well siblings often grieve for the loss of the sibling they once had, recognizing their relationship will never be the same (Marsh & Johnson, 1997). A number of participants also spoke about how their relationship with their parents had deteriorated due to the perception that their parents favored their ill sibling. In addition, many well siblings described a decline in their relationship with their parents as a result of the lack of attention they received from their parents due to the increased time they had to spend with the ill sibling. Current research supports this finding, explaining that the demands of mental illness often cause the well sibling to sense a reduction in parental attention and affection (McKeever, 1983; Schuntermann, 2007). Furthermore, a few well siblings described how their relationships with friends were negatively affected, as they began spending less time with friends to avoid discussing their siblings' illness. Research states that well siblings are often embarrassed by their siblings’ condition and avoid talking about it with friends, often causing problems with peers (Tsao et al., 2012).

Contributions to New Knowledge

Many of the above results were consistent with existing findings from other studies, although several findings from this study indicate that there is still quite a bit that we don’t know about the experiences and needs of well siblings. This study primarily contributed to new knowledge by offering firsthand accounts from well siblings. Given that much of the current literature describes the well sibling experience from an observer perspective (Hastings, 2007; McKeever, 1983), it is not surprising that the firsthand accounts offered by well siblings in this study have provided new insights, outlining the need for continued research in the field.

The current understanding from research suggests that parents, and sometimes grandparents are almost exclusively the primary caregivers of children and young adults with mental illness. In this study, three of the female participants reported that they functioned as the primary caregiver for their ill sibling at one point or another. This finding suggests that the prevalence of well sibling primary caregivers may in fact be higher than the literature states. It is not surprising that those who identified as caregivers for their siblings were female. We know from the literature that although caregiving by well siblings is rare, it is most commonly found among female well siblings (Sin et al., 2008). These participants had very unique relationships with their siblings and found it difficult to find support from the formal healthcare system when sought. Although we know that support offered to well siblings is minimal if present at all (Sin et al., 2008), the participants in this study indicated that well siblings who are primary caregivers have unique support needs compared to other well siblings. These participants described difficulties when interacting with professionals, when seeking information in order to care for their sibling, and in getting support for their own well-being. Some participants as caregivers still reported positive effects from their experiences regarding attention to their own health. For these participants, their siblings' illness offered a distraction from their own problems, and the motivation to seek treatment and recover from their own health issues. In this study, this finding was restricted to those siblings who were also the primary caregiver of their ill sibling. It is unclear whether this finding holds true among other well siblings, or even among other well sibling caregivers. It would be beneficial for future research to address in more depth the impact that the ill siblings' mental health problems have on the well siblings' perception of their own health and mental well-being.

Furthermore, this study provided new insights regarding the impact of these experiences on participants' basic values, leading them in particular to place a higher value on education and hard work. Although current literature does describe well siblings who do more work around the house in order to lessen the burden placed on their parents (Sin et al., 2008), the results from this study suggest a different reasoning behind the increased value placed on hard work. Specifically, the value on hard work in this case is associated with academic success, due to the age of participants and their enrollment in university or college. Many participants explained that their sibling had experienced many academic difficulties, and they thought that some of their mental health issues had stemmed from disappointment with academic failures. Future research should address the importance of this finding, and whether or not an increased value placed on academic success is a common sentiment shared among other young adult well siblings.

Furthermore, the participants explained how their siblings' illness had caused them to become more involved in helping others. For some participants, this meant getting involved with mental health campaigns and clubs on campus to promote mental wellness and reduce the stigma surrounding mental health issues. For other participants, this meant offering support to those around them who were also suffering from mental health problems. This involvement in mental health promotion and helping others is a finding that is not consistent with the current literature. It is possible that with the current lack of services available for well siblings, some individuals have begun to take the initiative upon themselves to create improved support options for family members of mentally ill patients. It would be interesting for future research to address the impact that the experience of living with an ill sibling has on well siblings' involvement in reducing stigma and promoting the mental wellness of others.

Implications for Healthcare Delivery

The results of this thesis have many implications for healthcare delivery. Primarily, it is clear that well siblings are reluctant to seek support for their own issues and have limited access when they do. Participants described perceiving that support options were limited, and feeling as though their problems were unimportant when compared to their siblings' issues, or someone else suffering from mental illness. Specifically, participants described limited healthcare resources on campus, and feeling as though other students needed the help more than they did. We know from the literature that well siblings who are able to receive support, and who are properly educated about their siblings' condition have better outcomes than those who are unable to receive support (Loukissa, 1995). Therefore, it appears essential that clinicians treating ill siblings extend consideration of need and support to siblings within the family. In addition, the author has already been approached by two student-run organizations that are involved in reducing the stigma surrounding mental illness, and promoting mental wellness on McGill University Campus, in order to use the results of this study to create resources on campus for well siblings. The engagement of university organizations indicates the need for a bottom-up approach to planning mental health care services on campuses, where the students are able to determine what services are most relevant to them. Mental health must also become a priority of policy makers in order to improve access to early diagnosis and intervention for mental health problems, and reduce the stigma surrounding mental health services. If mental health services were increased and normalized, well siblings would likely be more open to support as they would feel their problems were just as worthy of support as someone with a mental illness.

Furthermore, many participants spoke about their parents' reluctance to accept their siblings' mental illness. It appears as though some parents found it difficult to accept the diagnosis, while other parents simply did not believe in mental illness. While there may be a cultural implication to this concept, the reasons for reluctance to accept a diagnosis were varied in this particular study. This finding highlights the importance of greater public awareness regarding the prevalence of mental illness, the availability of effective treatments, and the need to reduce the stigma associated with mental illness. If mental illness were viewed in the same manner as a physical illness, it would likely make it easier for parents to accept the diagnosis and work towards supporting their child's recovery. Full acceptance of the diagnosis by all family members is crucial in order to reduce tension among family members, and to promote family cohesion to work together to support the treatment of the ill sibling.

It appears exceptionally important to ensure that education about mental illness is extended beyond the primary caregiver to the entire family. It is clear from the results of this study that well siblings may be confused about the details of their siblings' illness. Education and informational resources are needed in order to improve the caregiving capabilities of well siblings as well as to increase the role of the well sibling in the support of the ill sibling. Many participants stated that they would have liked to be more involved in their siblings' care, and would have appreciated being able to reduce the burden experienced by their parents, but were unable to do so because they didn't have a full comprehension of their siblings' illness.

Finally, an important finding is that almost all of the participants stated that they would have appreciated a group therapy session with their entire family. Participants believed this would have promoted honesty and communication among family members, and would have aided them in understanding their siblings' illness and how they could become involved in supporting them. Research supports the benefit of support groups, and family sessions in offering well siblings an opportunity to discuss their concerns and emotions, but states that these support opportunities are difficult to find for well siblings (Schuntermann, 2007; Sin et al., 2008; Stålberg et al., 2004; Tsao et al., 2012). It is clear from this study that well siblings continue to search for support options and continue to experience difficulty in finding these support options. Well siblings would benefit greatly from an opportunity to receive support with the rest of their family in order to learn about healthy coping strategies, and how to work together cohesively to support the ill sibling without jeopardizing family dynamics. The results of this study highlight the need for healthcare professionals to consider the well sibling when planning services for the ill sibling and their family. Including well siblings in the care of the ill sibling has the potential to yield benefits for both the well and ill siblings, as well as the family as a whole (Tsao et al., 2012).

Limitations and Future Directions

The limitations of this study are primarily related to the participant sample and the methodology. The small sample size and limited local recruitment (as an exploratory study) reduces the likelihood that focus group participants are representative of the Canadian population of well siblings, and the generalizability to other settings and populations. Although the focus groups included a convenience sample of participants from various backgrounds, it is likely that they did not encompass all well sibling characteristics and experiences, such as number of other well siblings present in the family, relationship to the ill sibling (blood-related, step-sibling, half-sibling, adopted sibling), family situation (two-parent home, one-parent home, divorced parents) and the age of the well sibling. It is likely that different types of well siblings encounter different experiences with their ill sibling, and may have different support needs. In particular, due to the exploratory nature of this study, only those participants who had siblings with anxiety and/or depression were included. Therefore, this study only offers results that speak to the experience of living with a sibling reportedly diagnosed with anxiety and/or depression. There is a range of other mental illnesses that a person can suffer from, and it is possible that siblings of these individuals may have different experiences and needs due to the nature and severity of the illness within the family. Furthermore, due to ethical constraints, this study only included well siblings who were age 18 and over, and thus only offers results from young adults who had lived with a mentally ill sibling. Younger well siblings may have different needs and experiences from young adult well siblings. Further research on younger well siblings, as well as well siblings of people with different mental illnesses (schizophrenia, psychosis, etc.) is needed.

Additionally, data collection and analysis were not carried out until data saturation was achieved. This thesis aimed to explore the well sibling experience of mental illness, and as such it was not expected that data saturation would be accomplished through three focus groups. Although data saturation was not reached, this study can still be considered methodologically sound due to the prolonged and intensive data collection and analysis phases (Green & Thorogood, 2013). Despite this, the lack of data saturation has some implications on the results of this thesis. The results presented in this work may be incomplete in describing the full range of experiences of the well sibling. Therefore, future studies should aim to recruit a larger, diverse sample and should continue data collection and analysis until data saturation is achieved, in order to present the full range of experiences of well siblings.

It is important to consider that the majority of the participants in this study self-identified as Caucasian (82%). This indicates that the results are likely non-representative of the McGill community, which is very multicultural (22.5% of all students are international), nor of Montreal or Canada as a whole. As a result of the reported backgrounds of the participants in this study, very little cultural variation was noted in the experiences of well siblings. It is possible that the predominance of Caucasian participant volunteers may be, in part, a reflection of the reluctance of people from other cultures to speak openly about mental illness. Additional research with well siblings with a larger sample and including a variety of cultural backgrounds is needed to understand the effect that culture has on the well sibling experience. Particular recruitment strategies, and perhaps methods, to ensure a diverse sample should be adopted in future studies to encourage participants from other cultural backgrounds to engage in research.

An additional limitation is that the participants in this study were all from an urban, largely Anglophone environment. Furthermore, all of the participants were pursuing a form of higher education (CEGEP or university degree) and are therefore considered to be well educated and from an economically advantaged background. It is possible that people from rural areas, and lower socioeconomic backgrounds would have different experiences, as well as different needs for support than the participants in this study. It is also likely that support and information services differ by region, and would be less abundant in rural areas. It may be enlightening to conduct similar focus groups with rural and low socioeconomic Canadian populations to note the potential differences in results; however this was not possible within the scope of this study. Furthermore, the focus groups included predominantly female participants (11 out of 17 participants), and thus the results may be limited by an overrepresentation of the female perspective. We know that men are less likely to seek healthcare services and support than women (Addis & Mahalik, 2003), and therefore the abundance of interested female participants may simply reflect men's lack of desire to share their problems with others.

Details of the family structure of each participant were not collected, and as a result this study is limited by the inability to interpret the effect of family structure on the variations that were found and reported in well siblings' experiences. Given the current lack of research of the well sibling experience, this thesis study was concerned with providing an exploration of a variety of experiences, as opposed to focusing on a singular family structure and the resulting experience of the well sibling. There is, however, evidence that family structure and dynamics affect lived experience (Carlson & Corcoran, 2001), and therefore future studies should address various family structures and should attempt to correlate family structure with variation in well sibling experience.

This study is also limited by the use of focus groups as a methodology. Due to the nature of dynamics within groups, it is possible that not all participants contributed as much as they may have liked; on the other hand, focus groups may be more encouraging of other participants to share their stories. The author tried to elicit relatively equitable participation from all participants by prompting those who were less vocal with additional follow-up questions. The author observed considerable variation between focus groups, as the extent to which they appeared comfortable, how talkative they were, and the general dynamics. Multiple focus groups were conducted to ensure varied group dynamics, and to account for variation in responsiveness between the groups. Unlike individual interviews, focus groups are difficult to assemble, as they require the coordination of many individuals. Three potential participants declined participation following the screening call, as they were unavailable for the selected focus group dates. Individual interviews would have allowed these participants to coordinate with the author to select a more convenient time and date. Despite these limitations, focus groups were appropriate for the context of this exploratory study as they are typically less invasive, and offered well siblings a supportive environment to discuss their experiences.

A larger qualitative study involving a large, diverse sample of well siblings from varied backgrounds could yield more confidence in results that are generalizable. Also, future research could involve different methods, such as individual qualitative interviews and/or a mixed-method study to provide more depth and breadth of understanding of well siblings' experiences, needs, and factors related to positive or negative experiences. In addition, a longitudinal study that addresses how the experiences of well siblings change over time (as was often reported in this study), and how this might impact their support needs and their support and information-seeking behaviour, would yield further insights. Such research would assist healthcare providers, and other professionals in improving the support offered to well siblings throughout their lifetime, and not simply in the diagnosis stage of their ill sibling.

Finally, it is important to acknowledge that the results of this thesis were produced in a learning context, by a novice researcher. To reduce the extent of this limitation, two of the thesis committee members (MSc supervisor and a family doctor who was a member of the thesis advisory committee) were present for each of the focus groups, allowing them to become familiar with the data.

These committee members were then consulted throughout the coding and analysis stages in order to gather different perspectives on the data and to determine the resultant themes presented in this thesis. These two committee members contributed feedback and ideas to establish the coding framework for application and analysis of the focus group transcripts, thereby increasing the likely validity of the findings (Green & Thorogood, 2013).

Conclusion:

The research conducted for this thesis contributes to our knowledge of the experiences of young adult well siblings who live with siblings who have anxiety and/or depression. The results of this study offer a greater understanding of the experiences and needs of well siblings, how they seek and receive information and support, and how these services can be improved. Comments from participants were broken down into six primary themes: impact of illness on family dynamics; the role of the well sibling; positive impact on well sibling; negative impact on well sibling; information, support, and professional services; and advice to others.

The results of this study, as well as the current literature, indicate that the well sibling experience contains both positive and negative aspects. Results indicate that the experience of living with a mentally ill sibling can negatively affect relationships with family and friends, personal and emotional health, as well as academic functioning. The experience also has positive aspects, including a positive impact on family dynamics, an opportunity for personal growth, and a chance to reexamine individual values. Although many participants would classify their experience as overall negative, all well siblings were able to find a positive aspect of their experience, thus highlighting the resiliency of young adult well siblings. The results of this thesis also contribute new knowledge about how the experiences of well siblings offer a sense of personal empowerment, encouraging these individuals to become involved in fighting for mental health causes in their community. Further research is needed to address the significance of this result.

The present results are in agreement with current literature and indicate that well siblings desire an opportunity to share their experiences with others in a supportive environment. The focus groups used in this study offered the participants this opportunity, but it is clear from the results that well siblings would benefit from increased supportive resources. Many participants spoke of a desire to be involved in family group therapy, but found it difficult to find this type of therapy available. By fostering open dialogue about the patients' condition among all family members, clinicians have an opportunity to encourage well siblings to become more involved in their ill siblings' care and to lessen the caregiving burden faced by their parents. In addition, group therapy sessions would offer an opportunity for well siblings to seek support and to ask important questions of clinicians in order to obtain valuable information about their siblings' condition. In general, participants seemed to use a variety of Internet sources, as well as textbooks from related university courses to seek information about their siblings' condition, but it is clear that well siblings would benefit from more structured information about their siblings' condition.

The results of this thesis concluded with a section detailing advice from participants to others. Well siblings had plenty of advice to share with other well siblings like themselves, parents, and professionals. It is clear from the advice given by participants that well siblings require open and honest communication from family members in order to promote healthy dynamics, and encourage close bonds between siblings. Participants indicate a strong desire to become knowledgeable about their siblings' conditions in order to be involved in their lives. The advice given by participants has many implications for both parents, as well as professionals in order to work together to improve the support and informational services offered to well siblings. This study will provide useful information to professionals working in the healthcare system to improve the support they offer well siblings, and will encourage investigators to conduct further research to gain a deeper understanding of the experiences of well siblings, and their support needs.

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Appendices:

Appendix 1: Consent Form

“Mental Illness in the Family: Investigating the Sibling Experience”

Investigator: Alexandra Dimmer, MSc candidate McGill Department of Family Medicine, Supervisor: Susan Law, PhD, VP Academic Affairs, St. Mary’s Hospital Center (SMHC).

Consent Form for Focus Group Participants

Purpose:

The purpose of this study is to explore and describe the experiences of individuals with siblings suffering from anxiety and/or depression. The aim is to contribute to better public and professional understanding of siblings’ experiences of mental illness in the family, and provide information to improve care and professional support for well siblings.

Voluntary Participation and Withdrawal:

Participation in this study is voluntary. It is your choice whether or not you take part in this study. The decision you make will not affect your access or your sibling’s access to healthcare and any other services available to you. You are free to withdraw from this study at any time. You may refuse to participate. In the case of withdrawal from this study, you will be given the choice as to whether or not any information collected up to the point of withdrawal for the purpose of this research may still be used in the analysis of the results.

What You Are Asked to Do:

You are being contacted because you expressed interest in participating in a focus group to share your experiences. You are receiving this consent form so that you can familiarize yourself with objectives for the study and this form prior to participating. You will be asked to sign this form at the meeting where we can answer any further questions before you agree to participate.

At the meeting, we will also ask that you complete a brief form with basic information about yourself (age, sex, family situation, etc.) when you arrive.

The focus group will be a group interview with 4-5 other young adults like you, who are living with a mentally ill sibling. There are no right or wrong answers to the questions we will ask you; we want to hear from your perspective about what it is like to live with a mentally ill sibling.

The focus group will be led by an experienced researcher and last approximately 45-90 minutes, and your involvement in this project will end once this focus group is complete.

Benefits:

Some people find it worthwhile to share their experiences, and it may be helpful to your own situation if learning from others' experiences that may be similar or different from your own. The results of this study can be made available to you upon request.

Risks:

Participating in this study will take some of your time. In studies such as this, some participants occasionally feel emotional or overwhelmed when sharing personal experiences. You can take a break from the focus group discussion if you need. You can rejoin the discussion at any time during the session, or you can choose to end your participation. The research team will respect your choice. The investigator will provide a list of local resources for professional support and counselling for participants as needed or requested.

While the importance of confidentiality will be explained to the group, the researchers will have no control over what participants do or say once they leave the focus group meeting. As such, you should be aware of the possible risk of loss of confidentiality should other members of the focus group discuss details of the session afterwards.

Compensation:

You will receive a small honorarium of $20 to cover any travel expenses incurred to travel to and from the meeting and in appreciation of your participation.

Confidentiality:

The focus groups will be audio-recorded. These recordings will be used to make a typed-transcript of the session prepared by the investigator, and then will be destroyed after 5 years. Only the investigator and her supervisor will read these transcripts to analyse these experiences according to common themes and summarise the results. All names or references to specific persons will not appear on the transcripts, so your identity will be protected. Quotes used to illustrate particular results will not be attributed to individual participants. Participant's statements and results of the focus groups will be presented anonymously (no names of the participants will be used) in the researcher's MSc Thesis, scientific articles, presentations to healthcare and educational providers, and at scientific conferences.

No one will be able to identify who you are when we present what we have learned from this study. All information we have collected about you for this study will be destroyed five (5) years after the end of the project. All electronic information will be kept on the investigator's password-protected computer in her office at St. Mary's Research Centre. All hard copies will be kept in a locked cabinet only available to members of the research team. The McGill Institutional Review Board, or an appointed independent monitor may access your files for quality assurance purposes. The research team is committed to keeping all information confidential, though total confidentiality cannot be guaranteed due to the nature of focus groups, as it will depend on the discretion and respect for privacy of the focus group participants.

Contact Name:

If you have any questions about the study, you may discuss them with the investigator, Alexandra Dimmer at (514)-826-6048, or the project supervisor, Dr. Susan Law, at (514)-345-3511 ext: 3142.

You may also contact the St. Mary's Hospital Ombudsman if you have any concerns or complaints about this project: Ms Sarah-Beth Trudeau, at 514 734-2618.

Consent Statement:

By signing below, you are agreeing to participate in this research study. Make sure that any questions have been answered to your satisfaction, and that you have a thorough understanding of the study.

I have read this consent form, and have had the purpose of this study, the study procedures, and the risks and benefits of participation explained to me. Any questions that I had were answered to my satisfaction. I voluntarily agree to participate in this study. I do not waive any of my legal rights by singing this consent form. I will receive a copy of this signed consent form for my records.

Participant's Name (Print)	Participant's Signature	Date
Name of Person who Obtained Consent (Print)	Person who Obtained Consent Signature	Date

Appendix 2: Recruitment Poster

Do You Have a Sibling with a mental illness?

We Want to Hear Your Story!!!

If you are between 18-25 years old and living with a sibling who has depression and/or anxiety, you are invited to participate in a focus group to discuss your experience. The focus group will last 45-90 minutes, and you will be compensated for your time. This study is part of an MSc thesis at the McGill Department of Family Medicine.

Your participation will contribute to a better understanding of the support needs for well siblings like yourselves

Please contact Alexandra Dimmer for further information

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Appendix 3: Recruitment Strategy

List of Where Recruitment Materials were Sent

E-mail Recruiting:
- McGill Kinesiology Department Undergraduate Students
- McGill Family Medicine Department MSc and PhD Students
- All Postgraduate Students at McGill (sent through the Post Graduate Student Society e-mail listserv)
- All students enrolled in a Mixed Methods Class (DENT 672)
- All students enrolled in a Participatory Research Class (FMED 604)
- Epidemiology Student Society listserv
- AUS listserv (Arts Undergraduate Society McGill)
- SUS listserv (Science Undergraduate Society McGill)
- MUS listerv (Management Undergraduate Society McGill)
- McGill Synchronized Swimming Club Members
- McGill Soccer Team Members
- McGill Rowing Club Members
- StudentsInMind Conference Listserv
- McGill Support Network Members
- Unleash the Noise McGill student Club members
- All student volunteers for Making Waves (sent through an e-mail listserv to all instructors)
- Zeta Psi McGill Fraternity Members
- Delta Kappa Epsilon McGill Fraternity Members
- Phi Kappa Pi McGill Fraternity Members
- Gamma Phi McGill Sorority Members
- Kappa Alpha Theta McGill Sorority Members
- Kappa Kappa Gamma McGill Sorority Members

Social Media Recruiting:
- The author’s personal Facebook page
- The McGill Anatomy and Cell Biology Department Facebook Page
- The International Greek Letter Community at McGill Facebook Page

Printed Ad Recruiting:
- An add was posted in McGill Classifieds
- Ads were posted at the McGill Gym
- Ads were posted in each of the undergraduate residences on McGill campus
- Ads were posted in the McLennan Humanities library

Appendix 4: Participant Screening Tool

Participant Screening Tool

Name: _________________________ Reference Number: ______________

Telephone: _____________________

General Information:

Sex: _________________________ Age: ___________________________

Sex of Ill
Sibling: ________________________ Current
Age of Ill Sibling: _______________

Number of
Children in Family: _____________ Number of Years
Lived with Ill Sibling: ____________

Current Living Situation (at home with sibling, away from home, with family…):

____

Information on Ethnicity:

Your Country of Birth: _________________ Your First Language: _____________

Your Parents
Country of Birth: ______________________

Please tick the boxes that best describe your ethnic background, (it is possible to specify further):

☐ Caucasian/White
☐ Aboriginal:
☐ African descent:
☐ Caribbean:

☐ European origin:
☐ SE Asian
☐ South Asian

Other (Specify):

____

Information on Occupation:

Occupation: ____________________ Full/Part time: _________________________

Program of Study: _____________________

Undergraduate/Graduate/Postgraduate: ____________________________________

Information on Sibling's Condition:

Please describe your ill sibling's mental illness as you understand it. While it is helpful to include your understanding of their medical diagnosis, it is not necessary if you are unaware of the specific diagnosis:

____

____

Appendix 5: Focus Group Moderator Guide

Focus Group Agenda

Mental Illness in the Family: Investigating the Sibling Experience

Detailed Moderator Agenda
Time: 45-90 minutes
Set up: Refreshments, name tags, conference table with recording equipment turned off until consent forms completed

I. Welcome: Thank you for agreeing to be part of the focus group. We appreciate your willingness to participate. We encourage you to participate openly and know that what is shared in this room is confidential. There are no right or wrong answers – your experience and opinions are important. We will be audiotaping the focus group discussion to be able to study the data in depth. Only our research team and the transcriber will review this tape. There will be no identifying information in the data, and if we use quotes they will not be attributed to any individuals. You will remain anonymous in any reports of this project.

II. Introductions:
Moderator (Student Principal Investigator: Alexandra Dimmer)
Moderator assistant (Principal Investigator: Susan Law)
Participants (Introduce themselves – first name, age, what they are studying or working on)

Meeting Purpose – Overview

Background talking points:

- Purpose of this study: We are conducting this focus group discussion to better understand the experience of living with a mentally-ill sibling and identify ways that care and support can be improved
- We really appreciate your participation – your perspectives are very important
- Signing of consent form and permission to record

II. Topic Areas and Discussion Questions
There are three areas that we would like to explore with you:

1. Your experiences of living with your mentally-ill sibling – your feelings and reflections about your experiences and emotions
2. Your thoughts on the information and support provided to you related to your own health – did you seek help at any time? If so, was it enough or what you would like to know or what else do you feel you needed or still need? How might you be better supported?

3. And any advice you would have for other well siblings in similar situations
4. What advice would you have for healthcare professionals or people working in the healthcare system in thinking about improvements for well siblings?

But before we start – just a little icebreaker exercise to get the conversation going and so we can get to know each other a little.

- Can introduce each other after 5 mins of speaking in pairs – give them 3-4 intro questions as reporters (e.g. how did they end up in the academic program? Do they have pets at home? Favourite holiday destination)

OK – let's get going with the first real question.

1. Can you tell us about your experience of living with a mentally ill sibling? I would like each of you to speak for about 5-7 mins about the whole story – from when it started to now. I will keep time and we can always come back for more later in the meeting – just want to give everyone a turn.

   Prompts:
   - What was it like in the beginning
   - Has the experience changed over time?
   - In what ways were your daily activities the same or different? Did your sibling's condition affect your friendships, family dynamic, daily routine, academics, etc.?

Pause – reflect on how these stories are similar or different? Any surprises? What did you learn? Are you interested in hearing more?

2. How would you describe this experience? What three words or descriptors would you use?

   Prompts:
   - Overall, was this a positive or negative experience?
   - In what ways was your health affected or not? How did you manage this?
   - Did you feel supported during this period by family and friends?

3. Tell us about the information you received from parents, clinicians or others about your sibling's condition?

   Prompts:
   - Was it enough, too much, or just right?
   - Were there other things you wanted to know or ask?
   - Suggestions for improvement?

4. We spoke briefly about support. Can you tell us about the types of support that you received?

Prompts:

- Who provided support? Friends? Family? Clinicians? Educational Providers?
- Was it enough support?
- Suggestions for improvement?

5. Based on these experiences, what sort of advice would you give to other young adults like yourselves, living with a mentally ill sibling?

6. And what sort of advice would you give to people running or working in the healthcare system?
7. Any final comments?
    - Was it interesting for you to participate in this focus group?
    - Why did you decide to participate?
    - Anything we could have done better to help this discussion?
    - Did you learn anything new or interesting in this session?

III. Closing

Thank you for your participation in sharing your experiences. What you shared today will help us better understand the experience of living with a mentally ill sibling, and how information and support provided to well siblings can be improved.

Appendix 6: List of Resources for Counselling and Health Services

Resources for Counseling and Health Services

If you are in immediate danger of harming yourself or someone else, please call 911.

For help with medical questions, contact info-santé at 811

McGill:
Health Services
Brown Student Services Building
3600 McTavish Street
3rd Floor
514-398-6017
Urgent Care Services: 8:30-4:30 pm daily
Appointments are also made on the 15th of each month for the following month for prescription renewals, STI testing, PAP smears, referrals, 3rd-party physicals, immunizations, and travel vaccines
Students must bring McGill ID card and provincial health care card

Counseling Services
Brown Student Services Building
3600 McTavish Street
Suite 4200
514-398-8149
One-on-one and couples counseling to individuals dealing with a wide range of psychological and emotional issues and academic and vocational challenges.
Also offers crisis drop-in services from 9:00-4:00 pm daily.

Mental Health Services
Brown Student Services Building
3600 McTavish Street
Suite 5500
514-398-6019
Urgent Care Services 9:00-3:30 pm daily
Appointments can also be booked by phone 9:00-5:00 pm daily
Students must bring McGill ID card and provincial health care card to each visit

McGill Eating Disorder Program
Provides individual therapy, nutrition counseling, meal planning, group therapy, meal support, psychoeducation and more
514-398-1050
edpclerk.mentalhealth@mcgill.ca

Suicide Prevention:
Suicide Action Montreal
514-723-4000

Emergency Mental Health Care:
Call Royal Victoria Hospital
514-934-1934 ext. 34271

Off-campus Clinics:
For a list of off-campus clinics and other resources in your area, visit www.mcgill.ca/studenthealth/offcampus

Appendix 7: List of Themes and Sub-themes

A list of the themes and sub-themes identified from the qualitative thematic analysis of results. There is no particular order to these themes or how they were discussed throughout the focus groups. Different themes were discusses at various times throughout the sessions.

Theme 1: Impact of Illness on Family Dynamics
• 1A: Relationship with ill sibling • IB: Relationship with parents • 1C: Parent and ill sibling relationships • 1D: Changes in behaviour of family members over time
Theme 2: Role of the Well Sibling
• 2A: Caregiver • 2B: Stuck in the middle • 2C: No role • 2D: ‘Friend’
Theme 3: Positive Impact on Well Sibling
• 3A: Personal growth • 3B: Lessons learned to apply elsewhere • 3C: Changed values • 3D: Attention to personal health • 3E: Adaptive coping behaviours
Theme 4: Negative Impact on Well Sibling
• 4A: Academic performance • 4B: Distress and worry about sibling • 4C: Personal and emotional health • 4D: Deterioration of relationships with family and friends
Theme 5: Information, Support and Professional Services
• 5A: Support and information seeking behaviour • 5B: Interactions with healthcare professionals • 5C: Perceptions of quality of care
Theme 6: Advice to Others
• 6A: Advice to other well siblings • 6B: Advice to parents • 6C: Advice to professionals (healthcare providers and policy makers)

Appendix 8: Search Strategy for Literature Review

Search Strategy: The search strategy that was used to identify relevant research is highlighted below. The search was conducted on February 20th, 2013, April 10th, 2013, September 12th, 2013, and January 21st, 2014. The databases PubMed, PsycINFO and MEDLINE were searched using the following subject headings: adaptation (psychological), child, chronic disease, family, mental disorders, parents (psychology), siblings (psychology) and caregivers (psychology). The following keywords were also used: chronic disease, family health, successful family, and sibling relations. The search strategy identified 155 potentially relevant articles. These articles were reviewed and narrowed down and those articles included appear in the references of this thesis.

Inclusion-Exclusion Criteria: This study explores the sibling experience of mental health burden on the family unit. As such, articles that highlighted the sibling relationship and the experiences of well siblings were chosen. Articles were included if they adopted a qualitative, quantitative or mixed methods approach. Articles were excluded if they met any of the following criteria:

1. Data about the sibling relationship in the context of other illnesses, as opposed to mental health disorders
2. No information provided about the well sibling experience or perspective
3. Articles published earlier than 30 years ago, as these were seen to be less relevant
4. Articles published in languages other than English