

# Mental Illness in the Family: The Experiences of Well Siblings of Young Adults with Mood and/or Anxiety Disorders

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## ABSTRACT

Current research on well siblings of individuals with mental illness focuses predominantly on adult siblings of individuals with schizophrenia, eating disorders, and psychosis. Few studies examine the experiences of young adult siblings of individuals with mood and/or anxiety disorders. We conducted focus groups with 21 post-secondary students, gathering their experiences of living with a sibling with mood and/or anxiety disorders. Our findings highlight the important role well siblings play in their sibling's care, and the significant health and social impacts of living with a mentally ill sibling, particularly during adolescence. The needs of young adult well siblings of individuals with mood and/or anxiety disorders must be considered in the provision of family-centred care.

**Keywords:** mood and/or anxiety disorders, depression, well sibling, qualitative research

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## RÉSUMÉ

Les études actuelles sur les frères et sœurs adultes de personnes atteintes d'un problème de santé mentale portent principalement sur la schizophrénie, les troubles de l'alimentation et la psychose. Peu de recherches se sont penchées sur l'expérience de jeunes adultes frères/sœurs de personnes souffrant de troubles de l'humeur et/ou d'anxiété. Nous avons organisé des groupes de discussion avec 21 étudiants de niveau postsecondaire et rassemblé leur expérience de vie avec un frère ou une sœur souffrant d'un trouble de l'humeur et/ou d'anxiété. Nos résultats mettent en évidence le rôle important des frères/sœurs dans les soins apportés à ce dernier ou cette dernière, ainsi que les répercussions en santé et les impacts sociaux sérieux du fait de vivre avec un frère ou une sœur souffrant de maladie mentale, en particulier à l'adolescence. Les besoins des jeunes adultes bien portants vivant avec un frère ou une sœur souffrant de troubles de l'humeur et/ou d'anxiété doivent être pris en compte dans la prestation de soins axés sur la famille.

**Mots clés :** humeur et/ou troubles anxieux, dépression, frères et sœurs en santé, recherche qualitative

Mental illness is highly prevalent among children and young adults. In Canada, the highest rates of mood and anxiety disorders are amongst youth aged 15–24 years (Findlay, 2017), and recent strategies published by Canadian policymakers promote child and youth mental health as a priority (Bartram & Mental Health Commission of Canada, 2012; Carver et al., 2015). Recommendations include a range of measures to prevent youth mental illness and support recovery, such as increasing campus-based mental health initiatives, and developing family-centred, community-based mental illness prevention programs (Bartram & Mental Health Commission of Canada, 2012). While these policy recommendations provide a plan to improve youth mental health outcomes, they overlook the needs of one group in particular: the siblings of individuals who are mentally ill. This study examined the experiences of young adults with a mentally ill sibling to highlight their needs, and to inform family-centred mental health policy and practice.

Although largely absent from policy, there is evidence regarding the impact of some mental illnesses and chronic health problems on “well siblings” (Barlow & Ellard, 2006; McKeever, 1983; Sharpe, 2002; Withers et al., 2014). Psychologists and health researchers have examined the needs and experiences of siblings of individuals with schizophrenia (Barak & Solomon, 2005; Gerace et al., 1993; Landeen et al., 1992), psychosis (Bowman et al., 2014; Ewertzon et al., 2012; Sin et al., 2008; Sin et al., 2012), and eating disorders (Areemit et al., 2010). Siblings of mentally ill individuals can feel neglected by their parents and healthcare providers (Abrams, 2009), be required to assume caregiving burdens (Hatfield & Lefley, 2005; Leith et al., 2018; Leith & Stein, 2012), and frequently experience grief and loss (Riebschleger, 1991), shame and guilt (Stalberg et al., 2004), as well as internalized stigma (Liegghio, 2017; van der Sanden et al., 2015). Finally, life-course analyses demonstrate that mental illness in one sibling has “ripple effects” on others, such that individuals have lower levels of education and employment than those with no ill siblings (Wolfe et al., 2014). There is also some evidence that well siblings can derive benefits from their experiences, including greater mental health knowledge (Sin et al., 2016) and enhanced personal development (Sin et al., 2008). This study focused on young adult, post-secondary students who are siblings of individuals with mood and/or anxiety disorders. We chose this focus for three reasons. First, existing research focuses predominantly on the experiences of older adult well siblings of individuals with schizophrenia, psychosis, and eating

disorders (Lukens et al., 2004, 2002; Sanders et al., 2014). Less is known about how younger adults experience sibling mental illness, and about experiences with mood or anxiety disorders, such as depression, generalized anxiety, bipolar disorder, and obsessive compulsive disorder (Barrett et al., 2000; Stengler-Wenzke et al., 2006). Second, emerging adulthood (typically ages 18 to 25) is increasingly understood as a critical time in development (Wood et al., 2018). The events experienced during this phase, such as the illness of a sibling and the availability of relevant supports, can have implications throughout adulthood, including negative impacts on the education and employment of well siblings, (Wolfe et al., 2014) employment, and marriage. Finally, mental health on Canadian post-secondary campuses has become a major public health issue in recent years, and research highlights the need for accessible, campus-based mental health services (Canadian Association of College and University Student Services & Canadian Mental Health Association, 2013). We collected young adult, post-secondary students' narratives of their experiences of living with a sibling with a mood and/or anxiety disorder to increase understanding of the needs of well siblings, and to inform healthcare provision and campus mental health promotion strategies.

## METHODS

This qualitative descriptive study (Sandelowski, 2000) aimed to explore the lived experiences of young adult, post-secondary students who have siblings with mood and/or anxiety disorders. This design reflects our desire to present a nuanced account of individuals' lived experiences during the period of adolescence when shared with a sibling suffering from a mood and/or anxiety disorder.

Participants were recruited through posters that were placed around a selected university campus, disseminated through email, social media, and the study team's professional networks at the university and a local college. Eligibility criteria initially included having lived (during adolescence) with a sibling with depression and/or anxiety; self-declaring as "well"; and being able to participate in an English-language focus group. Potential applicants were screened by telephone to confirm eligibility and to consider diversity within the sample in terms of gender, age of participant, age of sibling, and type of mood or anxiety disorder. Applicants were asked explicitly if they considered themselves to be a "well sibling" during this interview. Shortly after recruitment was initiated, we expanded the eligibility criteria to include siblings of individuals with obsessive-compulsive disorder (OCD) and bipolar disorder. We did this based on guidance from our clinical advisor, given the prevalence and relevance of the broader category of "mood and anxiety disorders" that includes depression and anxiety amongst this age group, and given the number of respondents indicating siblings with multiple types of diagnoses within this broader category. The decision to categorize illnesses such as depression and bipolar as "mood disorders" and disorders such as anxiety or obsessive-compulsive disorders as "anxiety disorders," was based on the 4th Edition of the *Diagnostic and Statistical Manual of Mental Disorders*, which was the current version at the time that the study was conceived and the participants were recruited (American Psychiatric Association, 2000). All participants received an honorarium in respect of their time. This study, which was originally conducted as part of a graduate thesis project, was then further developed, and approved by the McGill University Institutional Review Board.

Focus groups were chosen because they provide a supportive environment to share personal stories and elicit generative group discussions; in particular, among groups of individuals for which existing supports are lacking (Casey & Krueger, 2000; Morgan, 1997). The group size (5–6 participants) was intimate

enough to encourage comfortable self-expression while also being large enough to generate meaningful discussion. Sessions were conducted in a neutral (non-clinical) space and the facilitators made efforts to quickly establish rapport with, and between, the participants. Members of the team de-briefed after each focus group to consider what went well, what could have been changed or improved, and to consider ways in which their presence may have influenced the discussion. While we were initially concerned that the inclusion of a physician with mental health training at the focus groups (as requested by the ethics committee) might inhibit discussion, the physician introduced herself to the groups as a learner herself, which seemed to mitigate the suggestion of professional hierarchy. The atmosphere at all sessions was cordial and supportive and divergent perspectives were seen as variations in experience rather than points of conflict or dispute.

- A semi-structured discussion guide was used to elicit rich narratives of living with a sibling with a mood and/or anxiety disorder (Mishler, 1991). The sessions began with an informal “icebreaker,” where participants were asked to speak in pairs and then introduce each other to the group. Participants were then asked to share a brief overview of their personal story of living with their sibling, after which we paused to reflect on whether and how the stories were similar or different and to highlight anything they learned from listening to others. The facilitator (SL) then posed questions for group discussion about how they received information about their sibling’s condition, if they received any support and from where, and any advice they might have for others. The guide included prompts to stimulate conversation about the impact of the illness on family dynamics, the role of the well sibling within the family in relation to their sibling’s illness, impacts of sibling mental illness on the well sibling, needs for information and support, and advice for other family members and healthcare providers. The experiences and feedback from the first focus group helped to shape the interview guide and format for subsequent groups. Each of these sessions was about 90 minutes long.
- Data analysis began during the focus groups as the facilitators processed the comments, asked follow-up questions, and summarized recurring ideas throughout the session on a flip chart which was reviewed together. Participants were asked whether any key ideas were missing, and if some of the ideas or issues could be grouped under common “themes.” This was used as a form of member-checking (Casey & Krueger, 2000). A summary of each session was prepared, including details about group dynamics, initial observations, and interpretations (Casey & Krueger, 2000). The audio-recorded sessions were then transcribed by one of the authors and were subsequently checked for accuracy against the sound recordings and corrected where necessary. An inductive thematic analysis (Braun & Clarke, 2006; Patton, 2002) was conducted in two stages by two separate authors (AD, LR). The first stage was conducted by the graduate student for her thesis, and the second stage was conducted by an independent qualitative researcher following the completion of the student’s thesis.
- A coding framework was developed in discussion with the study team incorporating both a priori categories embedded in the interview guide and additional concepts emerging from interviews. Organization of the data using open coding was undertaken by a senior qualitative researcher (LR). Discussion with the study team informed development of axial codes to map out the relationship between categories. Selective coding was then used to articulate a thematically organized narrative

account of the data. The constant comparative method was used to test the integrity of the coding framework and included searches for disconfirming evidence (Strauss & Corbin, 1990). As this is a qualitative descriptive study, we were not seeking saturation and focused rather on transparency concerning data collection and the internal coherence of our analysis as markers of quality (O'Reilly & Parker, 2013). HyperResearch software (version 4.0.1) was used to facilitate data coding and management.

## RESULTS

Twenty-one eligible individuals between the ages of 18 and 27 were recruited to participate. We initially planned to hold three focus groups, however, due to a higher than anticipated response rate, we included all interested and eligible participants. Thus, four focus groups (5–6 participants each), were conducted between February and April 2014. All participants were students pursuing post-secondary education. Participant characteristics are summarized in Table I on the next page. The thematic analysis yielded five main themes: (1) the complexity and burden of sibling mental illness; (2) the culture of secrecy; (3) the impact on family dynamics; (4) participant self-denial; and (5) positive aspects of the sibling mental illness experience. The findings are presented below for each theme with illustrative quotes from the transcripts of the focus groups.

### Complexity and Burden of Sibling Mental Illness

Participant narratives revealed the profound complexity of having a sibling with mental illness. Extended periods of high stress and family conflict were common. Many narratives described years of uncertainty during which their ill sibling was experiencing mental illness prior to receiving a diagnosis or gaining access to appropriate care. Many participants, some of whom were very young when their sibling's illness began, described themselves as struggling to understand what was happening. In some cases, they linked their sibling's illness to adverse circumstances, such as parental alcoholism and family breakdown.

The impacts of such experiences included the development of trust issues, becoming emotionally withdrawn and being forced to bear adult responsibilities beyond their years:

I had to be an adult even though I was still a teenager ... the hardest part of it was having to grow up so quickly. (TS2 M1)

I was just stressed all the time ... this constant weight on your shoulders ... I knew how difficult it was for my parents ... It's just been a very ... negative effect on my day-to-day life. (TS1 F1)

Unsurprisingly, educational performance could also be impacted, either because of the need to be present for the ill sibling during times of crisis or, over the longer term, because of participants' desires to distract themselves by keeping as busy as possible:

My sister was hospitalized. It was right during finals ... and it was like a six-hour drive. So we drove six hours, went to see her at the hospital and left the next day for another six hours. It was time consuming but it was [also] emotionally consuming. And when your sister is ... telling you, "I just want to die ..." it's hard to focus on school. So, yeah, it definitely impacted me. That was my worst semester at [university]. (TS1 F2)

**Table I**  
**Participant Characteristics**

Participant Characteristics	N = 21
Sex	
Male	10
Female	11
Age (yrs.) – average age = 20.6 $\pm$ 1.58 SD	
18–19	5
20–21	12
22–23	2
24+	2
Self-Identified Ethnicity*	
Caucasian/White	17
Southeast Asian	2
South Asian	2
European Origin	1
Relative Age of Ill Sibling(s)	
Younger	9
Older	10
Both	2
Sibling Illness	
Anxiety (including OCD)	7
Depression	9
Anxiety and Depression	3
Bipolar Disorder (previously known as Manic Depression)	2

*Note.* \*One participant identified as both Caucasian and Southeast Asian

It really messed with my head a little bit ... I didn't sleep very well throughout a long time ... it affected my grades at school a little bit because I'd just try to push myself to do as much as I could to get it off my mind. So, I'd be doing sports and clubs as much as I could and ... my grades would be dropping because I didn't have time to do everything. (TS2 M1)

Several participants also recalled the trauma of witnessing family members in an acute state of mental illness and the fear they felt wondering whether the same thing might happen to them:

I remember very vividly [my mom] being hospitalized ... and it was when I became aware that my sister was also going down, not the same path but similar ... I remember being absolutely terrified ... that it would happen to me and ... that the rest of my life was going to be like that. Having to watch the people I really care about being wheeled out in an ambulance cause they had to go to hospital. (TS1 F3)

### **Culture of Secrecy Surrounding Mental Illness**

A common narrative element to emerge in discussion was the culture of secrecy, within families, around the sibling's mental illness. Many participants had not been told about their sibling's illness and had found out about it only very belatedly or by accident. This added to the daily strain and confusion they experienced and had a negative impact on relationships within the family:

I didn't really get any information from anyone till way later on in what was happening. I didn't even know she was going to counseling ... She would just go out with my parents and be gone for a couple of hours ... There also really wasn't any support. I didn't know what was happening. (TS2 F3)

We were on a family trip and I was just looking for something and I found antidepressant pills in her bag. So me and my younger sister confronted my parents and then they just got mad at us because they thought that we were snooping through her stuff. We just told them they can't keep hiding it from us if that's what they've been doing. So they told us that since she was at university she started seeing a therapist and has been depressed. And then everything kind of fell into place but I don't think it should have been hidden. (TS3 F4)

The culture of secrecy sometimes extended beyond the family. Several participants recalled how they were enjoined not to share information about what was happening with anyone else. Apart from the burden of such a big secret, this also meant that they were unable to seek support even from trusted friends and confidants:

My parents were like, "You cannot tell people about [brother] ... "You don't want this kind of thing getting around." ... I just never wanted to have friends over ... There's no explanation I can give because even if I felt comfortable enough to be like, "He's bipolar," I wasn't supposed to do that ... It's hard not being totally honest with your friends. I mean my relationships with my friends didn't totally degrade but it was suddenly, "No, we can't go to my house." (TS3 F1)

My day-to-day life was just having this secret that I carried with me, even through the hallways of school ... I know that people definitely noticed a difference in me ... people couldn't really understand what was going on ... I would just be walking through the halls and I would think, "No one knows this about me, that this is happening." (TS4 F4)

Being unaware of their sibling's true circumstances led some participants to experience guilt for failing to support them. For example, one participant explained how she felt when she discovered, belatedly, that her sister had been self-harming:

I also felt really guilty because 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 ... She's obviously hurting and she needs help. So I felt confused, guilty and overwhelmed by everything. (TS1 F2)

Another, was similarly remorseful for having viewed her sister as lazy because she was unaware that her behaviour was linked to mental illness:

I have a lot of guilt for not being there for my sister through it all ... I used to tease her, make fun of her for not doing enough. And, now, realizing what she was going through and suffering and just letting her be on her own when she really needed me. (TS1 F4)

### **Impact on Family Dynamics**

Participants described a range of impacts on family dynamics. Unsurprisingly, tension and conflict within the family were common:

It's had a pretty rough effect on my family ... It causes a lot of tension between my parents and between my parents and my sister. It kind of scares me in the fact that my parents are fighting over this. (TS1 M2)

In some cases, out of necessity, participants became mediators as conflicts arose between other family members:

It's really hard with my dad because he's always complaining that she doesn't do anything ... and then I have my sister ... who's complaining about him and how he doesn't love her ... It's a lot of arbitration ... I've had to do that with my parents too. (TS1 F2)

One of the most widely discussed impacts on family dynamics was the concentration of parental attention on the ill sibling. While it is neither surprising nor inappropriate that an ill child should receive parental attention, the extent of the focus on the ill sibling left many participants feeling abandoned and unacknowledged:

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 just didn't notice when things were wrong with me because they were constantly taking care of her. (TS2 F1)

Any kind of minor achievement she does is completely blown up in my family's eyes ... She got pretty good grades last semester and my parents were incredibly happy for her. They took her shopping and all this stuff. I left last semester with straight A's and I got nothing from them and they were like, "Good job, keep going." ... I'm happy she's better but I would appreciate the same kind of enthusiasm they give her about her accomplishments. (TS2 F3)

My mom was always taking care of my sister ... I always had good grades, I always had friends ... so I think she just put me off because I was fine and it was always about my sister, so I was very angry, growing up, at my parents ... My mom was like, "We don't want to put your sister down by praising you" ... We don't care if you get good grades." And then I was always like, But I'm trying so hard, look at me." I just wanted approval I think. (TS4 F1)

### **Participant Self-Denial**

Closely mirroring the diversion of parental attention, was the phenomenon of participant self-denial expressed through minimizing their own accomplishments out of deference toward their ill sibling. A number



of participants described a reticence to share news of their own accomplishments in order not to seem boastful or to avoid casting their sibling in an unfavourable light:

I definitely understand that whole guilt thing. When I go home, if my brother's around, I have to control what I'm saying just so I don't end up accidentally bragging about my grades or stuff that I'm doing in school. (TS1 M1)

Even more striking, however, was the active suppression of emotional needs by participants who had come to feel that nothing they were experiencing merited attention when compared with their sibling's experience:

As someone who doesn't need help with depression or anxiety, I feel like my stress or issues aren't worthy of seeking help. (TS1 F1)

When my sister got sick ... whenever I would start to feel upset about it I would think, "Well, I'm not allowed to feel upset because I'm not the one with the mental illness. I would always feel guilty and I would be like, "I can't tell anyone. I cannot complain about this because I'm not the one with the mental illness." (TS4 F4)

Moreover, many participants described themselves as suppressing their own emotional needs to protect not just their sibling, but their parents as well. Seeing their parents struggling with the situation left them feeling that any expression of need would simply add to an already heavy parental burden:

The biggest thing for me was just trying not to burden my parents so I would take a lot of stress and just keep it on myself. And now that my sister is starting to do better I can talk to them more about how stressed I get with school but, before, I just internalized it all. (TS1 M2)

... if I'm experiencing problems or feeling depressed ... it's like I wouldn't want to put that on my parents since they're already dealing with that stuff so much ... I think this idea that I don't really need support or I should be going to support unless it's like super serious has been part of the reason why I've had problems with drinking in the past. (TS1 M1)

### **Positive Aspects of the Experience of Sibling Mental Illness**

While having a sibling with mental illness was not generally seen as a positive experience, a number of participants felt that, in some way, it had made them a better person:

I think that one of the core positives is making me a lot more empathetic as a person ... really trying to step into someone else's shoes before making a judgment on their behaviour. (TS3 M2)

It's gotten me into ... trying to get other people to understand mental health problems and how it can affect your life ... I'm involved in a club on campus that deals with it. (TS3 F2)

While it was more common for sibling relationships to have come under strain, a small number of participants also felt that their relationship with their sibling had been strengthened through the experience:

We were already really close but it just brought us even closer. (TS1 F2)

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. (TS1 M2)

## DISCUSSION

This study explored the experiences of young adults (aged 18–27) with a sibling diagnosed with mood and/or anxiety disorders. Participants described the impacts of having a sibling with mental illness, specifically during the critical period of adolescence.

Participants described the increased stress that their sibling's diagnosis created for them and their family. Tension and conflict among family members were common, compelling some participants to act as mediators and/or caregivers within their family unit. This theme aligns with previous literature, which has found that siblings can often be required to assume caregiving burdens (Hatfield & Lefley, 2005; Leith et al., 2018; Leith & Stein, 2012), although this literature is predominantly focused on adult siblings. Our study adds to this, highlighting that adolescent and young adult well siblings similarly take on caregiving responsibilities. The role of young caregivers in general is an area for further investigation. Moreover, because of the secrecy surrounding their sibling's diagnosis, and the complexity of the diagnosis itself, many participants experienced extreme confusion and developed trust issues toward friends and family, a finding that is not well described in existing literature. This work thus amplifies young adult well siblings' lesser explored experiences of distrust toward loved ones and of confusion or lack of clarity about their sibling's diagnosis. Participants also described a sense of guilt either for failing to support their ill sibling, or for failing to recognize their illness prior to a formal diagnosis. Although our participants did not speak about a sense of grief or loss (Riebschleger, 1991), this finding extends previous descriptions of shame and guilt among well adult siblings (Stalberg et al., 2004) to young adult siblings of individuals with mood and/or anxiety disorders.

Many participants also described themselves as having suppressed their own emotional needs to lessen parental burden, and to keep parental focus on their ill sibling. This aligns with previous findings that well siblings often feel neglected by their parents, and that their own needs are perceived as less important than those of their ill sibling (Abrams, 2009). Participants in the focus groups also described keeping their stress “bundled up,” as they did not want to overburden their parents. Previous studies report that siblings desire opportunities to discuss their personal experiences but have difficulty finding such opportunities (Sin et al., 2008).

Despite the many challenging aspects of living with a mentally ill sibling, some participants also spoke of the positive impacts their sibling's illness had on them. Literature supports enhanced personal development (Sin et al., 2008) among well siblings. The participants in our study echoed this finding, describing a sense of increased empathy for those with mental illness. Participants also spoke of a desire to engage in activism for mental health awareness—a finding that suggests that well siblings not only have enhanced knowledge surrounding mental health issues (Sin et al., 2016), but a desire to turn this knowledge into meaningful action. Taken together, our descriptions of the positive and negative impacts of having a sibling with mental illness support and extend scholarly understandings of the complexity and texture of well sibling experiences, specifically among young adult siblings of individuals with mood and/or anxiety disorders.

These results suggest the need to increase awareness of the impacts, on siblings, of young adults living with mood and/or anxiety disorders. While healthcare teams and families are understandably focused on the ill sibling, early recognition of the need for openness, and transparency within the circle of care, as well as

creating space for the well sibling(s) to express their needs, encouraging them to set boundaries with their ill sibling, and to exercise self-care<sup>1</sup> may help mitigate negative impacts such as disruption of education and future employment, alienation and erosion of trust within the family, and feelings of shame and guilt. Dedicated support services for siblings such as those provided by Rethink Mental Illness in the UK<sup>2</sup> and the Canadian Mental Health Association<sup>3</sup> provide a useful model for community-based services. Academic institutions are also recognizing the need to update student mental health policies and facilitate access to services for those in distress.<sup>4</sup> Finally, our results also identified positive opportunities emerging from the experience of having a sibling with a mood and/or anxiety disorder. Several participants described their experience as having brought them closer to their sibling and having led them to engage with mental health advocacy activities. While not everyone in this position will have such an outcome, it may be valuable for families and healthcare providers to bear this possibility in mind while navigating the complex waters of sibling mental illness.

### Contribution to New Knowledge

Our findings provide new insights on the experiences of young adult well siblings of individuals with mood and/or anxiety disorders, and their needs for information and support. We add to the existing literature, which focuses primarily on adult siblings of individuals with psychosis, schizophrenia, and eating disorders (Barak & Solomon, 2005; Bowman et al., 2014; Ewertzon et al., 2012; Gerace et al., 1993; Landeen et al., 1992; Sin et al., 2008, 2012). The results are a novel contribution to knowledge about the lived experiences of adolescents and young adults who have siblings with mood and/or anxiety disorders, a topic that is seldom described in the literature, particularly in the voices of well siblings themselves. While the diagnostic criteria have changed in the current 5th edition of the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2013), the findings remain relevant in terms of understanding and addressing the needs of well siblings of young adults with depression, anxiety, obsessive-compulsive disorder, and bipolar disorder. Our study will be of value to healthcare professionals caring for families that include children or young adults with mental illness, to those responsible for service delivery, and to researchers in designing future studies. There are particular challenges facing post-secondary students where timely access to psychological and counselling support is limited due to a variety of institutional, sociocultural, and personal barriers (Dunley & Papadopoulos, 2016; Lefley, 1989). Supportive services for patients and families typically overlook the needs of well siblings (Sin et al., 2008), and thus offer fewer resources to support them. This study highlights the importance of considering sibling wellness in future policy development as well as in the planning and allocation of health and social services on post-secondary campuses and within the community.

1. [https://www.huffpost.com/entry/sibling-mental-illness\\_n\\_59aeca9ee4b0dfaafcf2df44](https://www.huffpost.com/entry/sibling-mental-illness_n_59aeca9ee4b0dfaafcf2df44)

2. <https://www.rethink.org>

3. <https://cmha.ca/documents/children-youth-and-depression>

4. <https://www.universityaffairs.ca/news/news-article/mcgill-to-overhaul-its-mental-health-service-mode>

## Limitations

The small sample size limits our ability to generalize the results to the larger population of well siblings. The sample relied on volunteer respondents, and although recruitment efforts were broad, most participants self-identified as Caucasian (17/21 participants), from urban centres, and were English-speaking. This is likely not representative of the overall post-secondary population, with a high proportion of multicultural and international students. All participants were pursuing higher education, and thus not representative of the general population of youth. 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. Moreover, young adult well siblings who do not have access to post-secondary education and on-campus mental health services may have greater or different needs than those included in this study. We suggest that future research explore the experiences and needs of young adult well siblings outside of post-secondary institutions to improve community-based mental healthcare provisions as well.

## Areas for Further Research

Important questions remain regarding how best to meet the needs of adolescents and postsecondary students regarding information and support. The term, “well sibling,” while prevalent within scholarship, may require a re-examination; several participants in this study struggled with psychosocial challenges in the absence of formal mental illness diagnoses. Larger studies, involving diverse samples to include various sociocultural backgrounds and enable gender-based analysis, could identify potential solutions for different sub-groups. As above, this could also include considerations of siblings outside the postsecondary context. The experiences and roles of siblings as caregivers should also be investigated. Studies that broaden the participant pool and phenomenon related to sibling well-being will enhance the relevance of this work to other groups and settings. Specifically, we suggest that studies examine the experiences of well siblings of individuals with bipolar disorder and with obsessive-compulsive disorder.

## CONCLUSION

The results of this study contribute new knowledge about the experiences of young adults having lived with siblings who have mood and/or anxiety disorders, which include anxiety, depression, bipolar disorders, and obsessive-compulsive disorder. As shared in their own voices, participants’ perspectives spanned five themes that provide greater insight into the challenges of living with a sibling with mental illness, and the well sibling’s unmet informational and supportive care needs. The inclusion of the positive aspects of their experiences is perhaps an indication of resiliency within this group. Further research is needed to address the significance of these results.

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