Maggie Rodman, “Trinity 1” Mixed Media (relief), 125 x 92 x 20cm.
Violence Against Women in the Context of Mental Illness

Hidden Costs for Sisters Who are Caregivers

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There are important differences between the caregiving that occurs between sisters and their ill siblings and the caregiving that occurs when mothers care for their adult children. First, the sibling relationship is one of the most enduring in any family (Cicirelli). Therefore, the commitment to caregiving for a brother or sister has no foreseeable time limit and can become an extended, life-long obligation. Second, sibling family relationships are more horizontal and egalitarian than parent-child relationships and, with adulthood, connections between siblings become voluntary (Eriksen and Gerstel; Wu Shortt and Gottman). Consequently, a sibling can have difficulty exerting authority and control over the behaviour of another sibling and tensions may arise around willingness to continue a sibling relationship. Third, although both male and female siblings may be available to act as caregivers, sisters are typically more involved, having more contact, providing more support, and experiencing more emotional strain in their caregiving roles (Greenberg, Kim, and Greenley; Greenberg, Selitzer, Orsmond, and Krauss). This is true despite the fact that sisters also have more competing caregiving responsibilities, often acting a caregivers for dependent children, disabled spouses, and/or aging parents (Greenberg et al. 1999; Horwitz; Marsh and Dickens). Therefore, sisters who inherit or are assigned caregiving roles that would usually have been given to their mothers take on a tremendous challenge. In the absence of public narratives that address the experience of sister caregivers, the challenges they face are hidden from view.

One aspect of these challenges that receives insufficient attention is possible exposure to violence by the mentally ill sibling. Multiple population surveys across international contexts reinforce that the general public is fearful of people with serious mental illnesses because they believe them to be unpredictable and dangerous (Corrigan, Green, Lundin, Kubiak, and Penn). Mental health advocates work arduously to challenge such stereotypes because they create barriers to the community integration of diagnosed individuals. However, the focus on reducing stigma makes it difficult to have frank discussions about the reality that people with mental illness do commit violent acts, and the most common victims of their violence are female caregivers (Arboleda-Florez). Although these violent acts are committed by a small minority of patients, the threat and actuality of violence undoubtedly has an effect...
on the mothers, wives/partners, and sisters who are threatened. Yet this is an issue that is difficult to address when families, mental health professionals, and advocates are also committed to dispelling ideologies that suggest people diagnosed with mental illness should be locked away to ensure safety of the general public. For some of

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these women, it is possible to get help because there are discourses available that make it possible to name life experiences like “elder abuse” or “intimate partner violence” and seek help through appropriate networks of services. Yet sisters are uniquely isolated in these situations because there are not parallel discourses that identify them as caregivers that are vulnerable to abuse by mentally ill siblings. Therefore, the absence of this discourse also contributes to hiding from view the experiences of women fulfilling these roles.

The fact that we do not talk about sisters who are caregivers and the violence that they may face does not change the fact that women in our communities live with these risks. In the following section, I present excerpts from interviews with women who have survived such situations in order to demonstrate how they have been affected by the absence of a discourse that can describe their situations.

Three Sisters’ Stories

In the summer of 2004 I began a study investigating how siblings are affected by having a brother or sister diagnosed with a major mental illness. This study is still in progress. As a first stage to the investigation, I conducted in-depth interviews with ten men and ten women. All participants in the study were adults who had volunteered and signed informed consent forms for audiotaping of their interviews, and use of the information for research and publication. During the course of the interviews, three women revealed that violence had been part of their experiences with their siblings. In the following excerpts from their interviews, I have modified their names to protect their privacy and the privacy of their families.

Cindy’s Story

Cindy is a 23-year-old Asian-Canadian woman, unmarried, and attending university. Both of her parents are living in another city. She lives in the same city as her older sister and her older brother. Cindy’s brother first showed signs of illness when she was 14 years old and he was finally diagnosed with schizophrenia four years later. He is currently stable but receives no medical or psychosocial treatment.

Mental illness and violence enter the family. Cindy’s brother returned from a trip overseas and began behaving strangely; he was not the man they had known before. Cindy describes the beginning of her family’s ordeal with mental illness by saying:

It was really, really chaotic ‘cause we didn’t know what exactly it was. So actually in the beginning he was, he was really violent and mean and now he’s all nice and stuff so it’s kind of strange. But it was just scary. It was miserable. When I think back I can’t believe we all went through that. And at that age my father’s face looked so old and tired and my mom would cry a lot and my sister and I would just....

Her voice trails off. This was my first indication that something had happened that it would be difficult for Cindy to bring in to our conversation. Later in the interview she tells me:

He would fight with me and my sister and he’s obviously a lot bigger because he used to play sports and work out. So yeah, he would always say “Oh! I’m gonna kill you!” So I’ll be afraid at night. And if I were watching TV and he’d come into the room and just change the channel, I’d have to sit and watch whatever he wanted. Or if he had to use the bathroom and I was in there, I’d have to get out as soon as he wanted me to get out. He was mean.

Cindy describes four years of living under the tyranny of her brother’s illness. During this time she was unable to sleep, depressed, highly anxious, and experiencing panic attacks on a regular basis.

Responses. Cindy notes that it was difficult to discuss the situation with her parents or with anyone else. Her brother would not leave the house and the family did not want to involve strangers. She speaks of her parents’ response by saying,

I don’t think they knew what to do at the beginning, because first born male son in our culture is so important and for him to act like that.... We have to give him a lot of respect even if he’s being mean and different.... One time after he kicked my sister and she threatened to call the police, my mom said “No. We have to figure out something but we don’t know what’s wrong. Don’t call the police.”

Her mother’s reluctance to involve the police may have been reinforced by their experience when
they did call for help. Cindy says:

"It makes me so mad! And I noticed that they paid less respect to my father, because he had an accent, than to me and my sister. I hate that! They just look down on us. But I don't know if that's their whole attitude toward everyone. Plus, I don't like this, sometimes I wonder if he [her brother] is not getting any help 'cause he's Asian or just, does nobody get help?"

Therefore, dynamics attached to sexism and racism contributed to the illness and the violence in the family being unaddressed and unacknowledged as problems that required intervention. Moreover, as a sister, Cindy was not recognized as carrying a primary burden.

I was complaining to my mom about how much I hated him. She said "Patience! Why are you telling me this? I'm his mother. Do you know what I'm going through?" And that's why I was so frustrated. Even my aunts and uncles would be like, "Oh your poor parents." Well, what about me and my sister? We were going through some stuff!

The Aftermath. Currently, Cindy shares an apartment with her sister and her brother lives in the family home. Although his illness has become less disruptive there are ongoing tensions.

He lives at home now because he just keeps going back and forth between nice and violent. My parents moved away. So me, and my brother and my sister, we lived in the house. But then at times he got violent again and so we kept saying let's move out, I can't stand living with this guy. So we moved away and then he became nice again.

Cindy believes that the four years living with her brother's violence have had an impact on her own mental health, although she is reluctant to blame him and struggles to find ways to focus her negative feelings on the illness, or find other explanations.

"It just affected me more than anyone else because I was very, very weak... Look at how my brother's illness has affected me and then the fact that my sister and my parents, I'm the only one that's gotten a little weird... I should have been stronger.

I have so many friends that say I'm depressed 'cause my parents are divorced. And I don't want to blame everything on my brother but I think it does affect me a lot and I don't want it to. I try to deny it, but maybe... I do blame it on the illness, that's what makes it so, life so frustrating for me. Because I can't blame my brother; it's the illness.... If it was my brother and if he was just a mean person it would be so easy to cancel him out of my life, but it's the illness.

Cindy is unable to locate her experience in a discourse that provides an explanation for her reactions at the time when the illness began, or justifies her ongoing anxiety and depression in the context of uncertainty about what will happen in the future. The narrative that makes sense of her story for her is one in which she is weak and deficient. She is also encumbered because there is a discourse that says she cannot hold her brother accountable for his behaviour.

The Future. Cindy is able to describe positive aspects of her relationship with her brother. Despite her wish that her family did not have to deal with this illness, she notes "It's so much better to have him in my life, even with the illness." However, she has decided she will not have children because she is fearful: "If they're going to live his life then I'd rather not have kids." This statement makes her start crying in the interview. She anticipates that she and her sister will continue to be the primary caregivers for her brother into the indeterminate future: "I know I resent him... because we're all going to support him in the future."

Yvonne's Story

Yvonne is a 22-year-old woman, married with no children and attending college. Her family has been in Canada for several generations and their roots are European. Both of Yvonne's parents are alive but they are separated, and both are dealing with substance use problems. Yvonne lives with her mother and her older sister. She is the primary caregiver for her sister; there are no other siblings or available family members. Yvonne's sister was diagnosed with schizophrenia when Yvonne was 18 years old. Her sister is under psychiatric care and she has had recurrent relapses into psychosis.

Mental illness and violence enter the family. Yvonne recalls that the

"He would fight with me and my sister and he's obviously a lot bigger because he used to play sports and work out. So yeah, he would always say 'Oh! I'm gonna kill you!' So I'd be afraid at night."

family's early experiences with the illness centered around her sister's control of the home environment.

I was having to turn faucets on and off for her, flush toilets for her, answer a lot of really repetitive questions, usually about hygiene. And that's when I started having
Yet, she has no accompanying symptoms and their affect on people. Yet every reference to violence explanation for these experiences was making was just like, okay, we’ll buy her art supplies! That’ll be okay… so it was very, it was very stressful. I’d just have more and more breakdowns. I’d be crying every night for no reason and just, I guess when I was 19 I stopped going out. Period. Stopped talking to people, stopped going out. I just wanted to be at home with my sister and my mum if she was still around.

It was really hard, really tiptoeing around. And my mother just pushed me aside. She was like, we have to do whatever we can to make her normal. She’s gotta be normal. She’s gotta work again. She’s not sick. She’s going to get over this. It was kind of a denial thing happening. So all the attention went toward her, but it wasn’t supportive attention.

Yvonne’s attempts to seek help for herself have been unsuccessful.

I collapsed when things were bad. When she got stable I could collapse and I did... I was in the midst of something really, really extreme and I had to put off my school work. My expenses got more and more because the degree was taking so long and all these sort of things. But I dealt with it, knowing that it is a bit selfish. It just doesn’t seem to make sense, just a byproduct of somebody else’s illness. And my mom would say, ‘You’re not ill!’ and I’m like, maybe I am, at least I was almost convinced I was. I just didn’t know what was going on and I didn’t have anybody to talk to and I tried to see, I’ve seen two psychiatrists and was put on a waiting list and never talked to either one again.

Therefore, it seems that Yvonne will not give herself permission to become aware of the personal consequences associated with supporting her sister until she believes that her sister no longer needs her. The lack of success she has had with finding a psychiatrist to provide support for her in the caregiving role reinforces a message that the problems she experiences are not acute or urgent enough to merit prompt attention.

The Aftermath. Yvonne tells her story making a distinction between when she was living in the same house with her sister and when she moved out. She recalls her emotional turmoil when living with recurrent threat from her sister:

It was really affecting school. Like you know when I did my assignments, they were really good. But I just couldn’t always do it and I was getting increasingly more anxious and depressed and it was, it didn’t really seem like there was a reason for it. Like it did in my head, but I wasn’t diagnosed with anything.

Once again, we have a sister who knows something is happening to her but does not have the words to articulate it. The narrative that makes sense for her is that she is getting upset with no reason. She needs external confirmation before she can recognize her distress. Yvonne eventually leaves the family home hoping this will provide some relief, but

...From then on, I was having anxiety attacks. My mother wouldn’t talk to me for 3 months because I left. She just couldn’t understand why… I started antidepressants within a few months ... and my stomach was giving me a lot of problems. This IBS [Irritable Bowel Syndrome] sort of appeared at the same time and the only thing that stopped the IBS pain was the medication.

She later explains why it is difficult to talk about her own experiences of mental health problems.

You can’t pity yourself on some-
thing like that. When something like that is going on because somebody you love is in such a worse condition and you just do what you have to do. And you take joys in their small accomplishments and then reassuring them. But I get real, like I get haunted by certain images.

I was just going into my own anxiety and depression. My mother was just, ‘you’re selfish, you’re selfish, you’re selfish.’ Because I left and because all of a sudden my mom had to take on all this responsibility, what I’d been doing for years. And it is selfish in terms of, I wasn’t an understanding person.

On some level Yvonne understands that she needed to take care of herself, but she struggles with a belief that she should sacrifice herself to take on the role of caregiver. This is a message that is communicated explicitly by her mother and reinforced by narratives that she carries about what is expected of women who care about people who need care.

The Future. Yvonne cannot imagine a future without being in this role with her sister. The two are bonded by their sibling relationship and also bonded because they grew up together in a chaotic family environment in which her sister’s schizophrenia was only another chapter. Yvonne characterizes this by saying

I have an empathy with my sister. What hurts her will hurt me to the core as well. We were always in it together. You know we’re two kids who would talk to the police ourselves or take turns dealing with things or whatever went on we did it. We went through it together, so there is a sort of solidarity. It’s going to be my sister who is there for me at the end of the day. And that was frightening for a while because the only person who would be left is mentally ill, but I know she’ll get better.

She remains devoted to her sister even as she realizes “You will give everything to somebody who is mentally ill because you feel sorry for them and you can’t help it because you love them.” Therefore, she articulates her contradictory position as someone caught in a discourse that makes it difficult to distinguish between expectations attached to ‘caring about’ someone, from expectations attached to ‘caring for’ someone.

Sharon’s Story

Sharon is a 26-year-old woman, unmarried and working full-time. She is a first generation immigrant from an industrialized, English-speaking country. Both of her parents are alive but separated from each other. She has a younger brother who lives in another city. Sharon describes the gradual onset of her sister’s illness.

Mental illness and violence enters the family. Sharon describes the gradual onset of her sister’s illness and her responses at the time:

Sharon’s sister was diagnosed with schizophrenia when Sharon was 18 years old. Her sister is under psychiatric care but is quite unstable and in deteriorating mental and physical health.

Mental illness and violence enters the family. Sharon describes the gradual onset of her sister’s illness and her responses at the time:

She’d just get upset over nothing. She became very unpredictable, sporadic emotionally. Kind of emotionally manipulative and things like that. And she started to do, to get, really reckless with her physical self and her actions.

I was just too hard on her and I was just, kind of like the bitch of the family…. Like I was the one that took the brunt of the … I wanted them to see what was going on.

It is early in the interview and Sharon does not tell me right away what she means by “took the brunt,” but later she reveals,

She became very physically abusive and she’s a lot bigger than me. I’ve always been the smallest one in the family… She reacted a lot in anger and I reacted a lot in anger. Verbally, I was good with words and she was good with muscles…. It wasn’t severe. Like it was pick me up and push me against a wall. Or, squeeze my arm, or know, just push me against the bed and things like that. Punch in the face once or twice. You know, lot’s of scratch marks. And some head banging… I would say it was physical, but it wasn’t dangerous. Physical… like she never picked up a knife. She never threatened me in any real, like that I felt in any real danger.

When I comment on the on her characterization of this list of assaults as not threatening or dangerous, she has an excuse for her sister: “I might have seemed unsympathetic and other things that probably made her feel worse.” The narrative is made coherent by the juxtaposition of her role as “the bitch” against her sister’s need for sympathy. Sharon elaborates her narrative by casting herself as someone who provoked and perhaps deserved the assaults from her sister because she was not sympathetic enough. Apparently, she is reluctant to attach a notion of danger to the body of her sister, even though that body was capable of inflicting harm on her. She will not make the connection between what happened to her and violence.

Responses. Initially, Sharon’s family was reluctant to examine the possibility that her sister was ill. Sharon left the family home several times for brief periods because she could not live with how the family chose to cope with her sister’s behaviour:

It didn’t matter what I said or
how I reacted. I felt there was, it was beyond me what was happening. And that I couldn't fix it. Even though I really wanted to. And that no one in the house was, was reacting properly. Was realizing properly that this wasn't just that she was emotional and I was provoking her.

The family was confronted with the reality of mental illness when her sister made a serious suicide attempt and was hospitalized. Sharon said that her role in the family changed. She was no longer seen as the insensitive sister that provoked the sensitive sister, but she now expected to take on the role of caregiver. Because she had spent years trying to make them see the reality of mental illness when they didn't want to deal with it. Basically, most of the family most of the time just ignore it. It's pretty much come down to just me and my mother. I support my mother and my mother supports my sister… I come and give support when necessary.

Although Sharon says her parents have educated themselves about mental illness and come to accept that their oldest daughter may not attain the goals they originally envisioned for her, she also says that her brother and father remove themselves from dealing with her sister, only becoming available during periods of high crisis.

The Aftermath. Sharon removed herself from the family home because she realized that her exposure to verbal and physical assault was wearing her down. She describes a temporary respite from the pressures:

It was good because I didn’t have to worry about anything but me. I didn’t have to worry about whether she was around, and what mood she was gonna be in, what she was gonna say, and if I said something wrong, you know all that stuff. So it was great for a while.

However, this respite was short-lived.

You get drawn back into it. You can’t escape. Mostly it was my mother. Things started to get really bad, and there was no one, just her. So she was coping alone… Mum started to come to me for support. And that just grew and grew. And eventually it was every time something happened and every time something was going on. I spent hours on the phone to coach her through the hard stuff. Talking what I didn’t feel, but what sounded logical, sounded reasonable, you know. What I guessed and probably was wrong. I don’t know. Probably wasn’t the right role for the daughter to play, but someone had to. She couldn’t cope by herself.

Sharon goes on to say that this is a role she has not been able to relinquish, even when she is dealing with her own difficulties. She expresses that this is not a role for a daughter to play, signaling the non-normative expectation that she act as a coach for her mother’s parenting tasks. Yet she does not speak of the strange role she plays as the indirect and direct caregiver of a sibling who is a threat to her. When she speaks of “talking what I didn’t feel” to help her mother continue supporting her sister, I imagine that this is the closest she can come to articulating this dilemma in the context of the interview. She describes her survival strategies, noting “I kind of have that thing where you can remove yourself from being in it all and then go back to your emotions later. I can do that fairly well.” Perhaps this is how she maintains this contradictory position of remaining close when she would rather be far away.

The future. Sharon looks forward to a future in which she will continue to provide indirect care for her sister, eventually becoming her primary caregiver. She believes that her sister will only deteriorate further:

The future doesn’t seem very bright and there’s still that emotional connection to the person that you used to know. But it’s very painful to watch them kind of turning into something else.

Years of exposure to her sister’s illness has contributed to Sharon losing sight of the humanity in her sister:

Some people cause a lot of damage. And my sister does ruin relationships. You’re not capable of having a real, real interaction, real stability, real feelings of love or anything like that… You stop trying because it becomes too hard for yourself.

Sharon articulates her need to protect herself from the damage inflicted by the illness, but she does not name the illness, she names her sister. Throughout the interview there is this tension between attributing family problems to her sister and attributing them to the illness. Perhaps this recalls the tensions that existed in her family when they could not distinguish escalating symptoms from troublesome interpersonal dynamics. Sharon carries these tensions forward with her into an immediate future where she must support her mother, and a distant future where she will be left alone to support her sister.

From Stories to Strategies

This paper uses three women’s narratives to begin a discussion about the violence that women, particularly sisters, experience in families affected by mental illness. Because we do not talk about sis-
A discourse that says caring about someone means that you must care for that person, especially if you are a woman, silences discussion of emotional and other barriers that can contribute to unwillingness to care or ambivalence about caregiving.

Competing discourses silence them. A discourse that says we must not talk about the violence committed by people diagnosed with mental illnesses silences discussions of violence at the hands of loved ones. A discourse that says family violence unfolds between intimate partners or between parents and their children silences discussions of violence in other family configurations. A discourse that says caring about someone means that you must care for that person, especially if you are a woman, silences discussions of emotional and other barriers that can contribute to unwillingness to care or ambivalence about caregiving. Finally, a discourse that says women are selfless in their caregiving silences discussions about the burdens of caregiving and the toll it takes on their mental, physical and emotional health.

I have spent many years working with people diagnosed with serious and persistent mental illnesses and I believe that most of them are not dangerous or prone to violence even when they are acutely ill; the research evidence supports this belief (Arboleda-Florez; Estroff, Swanson, Lachichotte, Swartz, and Bolduc). However, when three out of ten women volunteering for my study described living with siblings who had threatened their lives and/or assaulted them, I realized that there are probably other women living in the same situation from whom we have not heard. Research confirms that family members who are involved in providing care, in close proximity and have high levels of contact with relatives that are mentally ill are at more risk of violence. These women’s stories teach us that there are aspects of their ongoing distress that are related to the exposure to violence, but there is also an emotional residue that is left behind when family members do not respond to support or protect them from the dangers posed by the mental illness that has entered the family. Family members need to understand that
References


Ronnie R. Brown was the 2001 winner of the Ray Burrel Prize for poetry and her third collection of poetry, Photographic Evidence, was short-listed for the Archibald Lampman Award. Her fourth collection, States of Matter, will be published by Black Moss in 2005.

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FOCUS

Even in sleep her mind can't settle. Like that myth about life flashing before the eyes of the near dead, she reviews her past. Errors, mis­ cues, misdeeds lingering far longer than needed to reinforce their point. As morning nears, things speed up, images shift, blur in and out of focus as if she were in the optometrist's chair the lenses flipping, as someone asks, 'Is this one clear? How about this one? Now let's try another. Is that better? Worse?' The pulsing buzz of the alarm brings her to her feet. Standing before she's fully awake, she pauses, waits for the room to solidify, for her now-open eyes to adapt to her terminal prescription.