



Stigma and public health policy for schizophrenia

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My involvement in the schizophrenia movement began when my sister Sherry was diagnosed with schizoaffective disorder in the late 1980s. In seeking support and information after her diagnosis, I became (and remain) active in the schizophrenia movement. Over the years, my family has adjusted to her illness. Although the disease is always tragic, we are fortunate to have a secure family, and my parents' continual patience and love have led my sister to a more solid place, relative to the earlier years of her illness. This improved situation continues to be difficult for my aging parents, however.

My sister's illness affected me not only personally, but also academically and professionally. The experience of learning about the health sector through my sister's involvement with it led me to study in the mental health field. It is common that people working as mental health practitioners have family members who are ill. I do not work full-time as a care provider because I prefer to work in the areas of human service research, education, policy, and organizational development. Although I maintain an active interest in clinical practices, particularly those involving family members, I believe working full-time in front-line services in addition to being part of my sister's life would create an overload of schizophrenia for me. I work primarily outside of the field but maintain an active involvement with my community support group and have many friends who either have schizophrenia or have family members who are ill.

As a mental health practitioner and as a nonbiologic (adopted) sibling of someone with childhood-onset schizoaffective disorder, I find that mainstream neuropsychologic schizophrenia sibling research [1–3], although heuristically useful, is not relevant to me. Relationship-based research is much

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more interesting for me because my sister's genes and mine are dissimilar and it is only our environment we have in common, rather than our lineage [4–6].

I have met many siblings of people who have this disease. I have found that most express concern about the complexities and uncertainties of planning for the future care of their family members [2,7–9]. The focus of this article is on strengthening capacities within families to plan constructively and proactively for the sustainable and continuous care of the seriously mentally ill. The evidence is clear as to the importance of family members in the short-term and long-term care of people with serious mental illnesses [10]. A survey of Canadian psychiatrists found that in working with the family, the top intervention in increasing compliance is educating the family and patient (48%) compared with focusing on regular appointments (following up, monitoring) (24%) or counseling and psychoeducation (17%). The other less common responses concerned psychopharmacology (choices, method, and dosage) and including family members [10].

My sister has responded admirably, courageously, and insightfully to her illness. My own experience with the disease, although a journey that has had its dark times, now seems more workable because my family is talking about future financial and caregiving plans. Talking about our fears of what the future may bring, as my parents age, has been useful to all of us, as we now are more able to plan for the future.

The Schizophrenia Digest featured a story on the lack of future planning among families with adult children who are mentally ill [11]. The story profiled my sister and my father (see Fig. 1). Being involved in raising awareness of an issue that affects her life was a positive experience for Sherry. The story highlights how even though we are working together as a family, we all are concerned about the future. Through my active involvement in the schizophrenia movement, I have become well aware of how isolation limits caregivers' abilities to develop sustainable plans and increases the risk of chaotic and traumatic experiences. I also am aware of how acute relapses lead to a poorer prognosis and increased cognitive impairment [12].

A few years after my sister was diagnosed, I planned to have my sister move from my parents home to mine. I completely underestimated the challenges that lay ahead as my sister moved some of her belongings to my home, which was (and still is) in a city 9 hours away from my parent's home. I was ill prepared for the demands of caregiving, and our cohabitation experience ended chaotically. Although Sherry and I shared many positive experiences during her summer stay in my home, our mutual decision for her to stop taking antipsychotic medications, which was supported by a psychiatrist she was seeing at the time, ultimately resulted in a psychotic relapse. I had to send her home to my parents in a much worse state than when she arrived. The summer experience was a painful lesson for both of us about the importance of compliance and acceptance. It was heartbreaking to witness Sherry's loss of capacity.

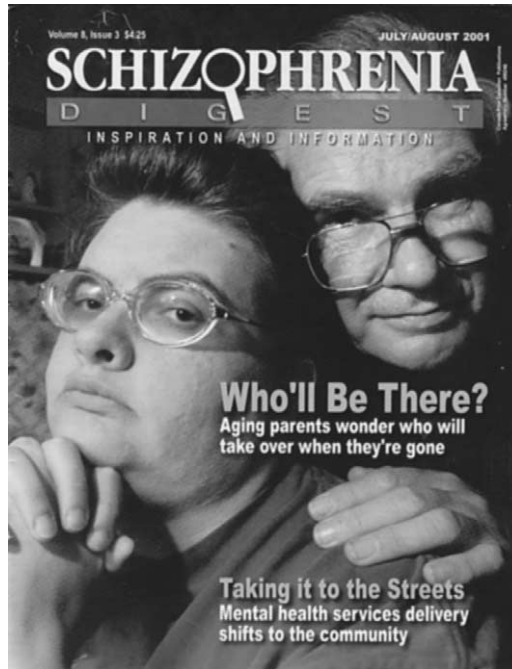


Fig. 1. Sherry counts on her dad Gordon for support, but both worry about the future. (Photo by Jason Scott. From Forsyth P. Who will be there? Families worry what will happen to ill children when parents are gone. *Schizophrenia Digest* 2001;8:16–19; with permission.)

Now, neither Sherry nor I doubt the importance of her medications, and the clarity of this insight will be most useful for us in the years to come. I learned that it is not reasonable for me to expect that I can care for my sister in my home. I also learned a lot more about Sherry. I came to appreciate what a bright, gentle, and caring individual she is; her witty sense of humor; and her wide range of interests. Today, my sister is a source of inspiration for me, and she is a champion of rights for the mentally ill and, with my father and me, she is active in the schizophrenia movement. Sherry has enjoyed being part of creating and narrating a community play about the stigma of schizophrenia, performing to local and national audiences. I am proud of her and recognize my family's good fortune in being able to cope, albeit perhaps clumsily, whereas many families simply cannot. The multiple challenges, from horrible side effects to not accessing appropriate care, are too much for some families.

Urgent need

Also reported in the Schizophrenia Society article in which my family was featured were the results of a survey by the Toronto Chapter of the

Schizophrenia Society. The survey related to the Chapter's encouragement of families setting up discretionary funds for trustees (family members or friends) to oversee the finances of people with schizophrenia. The findings of the survey were that 38% of caregiver parents are 65 to 74 years old, with another 27% being older than age 75—approximately 70% of caregivers are senior citizens. It was stated that too many families are not planning for the future [11]. The Society encourages parents to find alternative housing for their adult children (especially parents whose children are still living at home) before it is too late [10]. Toronto's results could be replicated in any Canadian city because the demographics are similar across Canada in terms of an overall aging and increasingly diverse population.

In Saskatchewan, the provincial chapters of the Schizophrenia Society are working with several aging parents, trying to find supportive housing for their ill adult children. Some of the parents are older than age 80. A group from the Regina Chapter is working on establishing long-term supportive housing for families facing urgent situations. Although responding to the emergency is important, the eventual aim is to prepare families well in advance of serious illness (or death) of aging parents so that there is continuity of care for a mentally ill family member. One of the major reasons for hospitalization is the death of a caregiver [13].

Similarities to the American situation

The *Schizophrenia Digest* feature on planning for the future stemmed from a report on an American research project funded by the National Institute of Mental Health about how families with seriously mentally ill members are planning for the future. Social workers at the University of Wisconsin-Madison are working on an innovative National Institute of Mental Health-funded research project studying aging American families whose adult children have schizophrenia. The study, launched in 1999, takes place over 5 years, and involves three interviews with the 300 participating family members. Based on data from the first round of interviews, in asking the question "How are families preparing for the future?" the researchers found that few families are tangibly preparing for the future by working out detailed plans with other family members, friends, and their other children [11].

The initial interpretation of the interview data is that the unpredictability of schizophrenia robs parents of the ability to plan for the future, leaving parents unsure about what kinds of decisions need to be made [11]. Other findings are that parents feel cut off from decisions mental health professionals make about their children [11].

It is disconcerting how many parents said they assume siblings will take over the eventual caregiving of the mentally ill family member. Siblings stated, however, that they do not plan to take over the level of caregiving their parents provided [11]. Given the high rates of suicide among people

with schizophrenia, this apparent gap between expectations of parents and siblings could be fatal for those who are ill.

Saskatchewan sibling connection

In Saskatchewan, a local informal group has evolved as a result of common family concerns about what an unplanned future may bring for people with serious mental illnesses and their brothers and sisters. My own goals in being involved with the schizophrenia movement and with other siblings are to strengthen my relationship with my sister and my ability to work collaboratively with her and my parents toward planning for the future. I know that isolation is a caregiver's enemy. Becoming more aware of other people's experiences and not feeling (or being) alone in my role as a caregiver is crucial. These are the reasons I am involved in this movement.

Based on personal experience, I have discovered models and concepts that have changed my approach to responding to schizophrenia's perpetual presence in my family. I have shared my approach with family members and mental health professionals across Canada at various conferences and workshops. Talking with people around Canada has helped me to see the similarities in the challenges faced by many families as parents age and increasingly worry about what will happen to their children when they die.

Impact of schizophrenia on family members

Mental illness has profound consequences for the entire family, although each family member may respond differently. Although not well covered in the literature, people observing and responding to patterns of caregiving in families find that there are common response patterns shown by children, partners, and siblings [4].

Regardless of one's role within a family, there are common outcomes for most families when a member is mentally ill, including social isolation, secrecy, and a sense of stigmatization. Grounded in mythology, the stigma that surrounds mental illnesses is pervasive, and most people feel they have to face the disease silently [14]. In contrast to caregiving for less stigmatized disabilities or illnesses, in which social support, sympathy, and financial compensation exist, there is little support for people whose relatives' chaotic behavior results in time away from work or sleepless nights. An employee caring for an aging or physically ill family member generally is allowed some flexibility around work responsibilities, perhaps being able to work flexible hours and sometimes able to access paid sick leave for family caregiving activities. People whose relatives are mentally ill typically find there is little sympathy within the workplace for their hard-to-define difficulties; such people generally resort to isolated and unsupported caregiving. For this reason, the support offered by and within groups such as the Schizophrenia Society is essential.

Stigma

Public attitudes toward people with schizophrenia were surveyed in Canada as part of the World Psychiatric Association's "Global Program to Fight Stigma and Discrimination Because of Schizophrenia." A survey was conducted with more than 1600 respondents (≥ 15 years old) residing in two adjacent rural and urban health regions. With a 71% response rate, researchers learned that half of the participants had known someone treated for schizophrenia or another mental illness [15]. Two thirds of the respondents who had known someone treated for a psychiatric condition identified a biologic cause, usually a brain disease [15].

Respondents were more likely to "social distance" in more intimate scenarios. Specifically, 80%, approximately four out of five respondents, thought they would be able to maintain a friendship with someone with a mental illness. With more intimacy, people were more distancing, and only half felt they could live with a mentally ill person. The highest social distancing is in intimacy; only 25% felt they could be married to someone who is mentally ill [15]. Another finding was that greater knowledge led to less social distancing and that people older than age 60 were the least knowledgeable and had the greatest social distancing [15].

The implications of this research are useful. Over the years, the Schizophrenia Society has been involved in a variety of media and awareness-raising campaigns. With Stuart and Arboledola-Flórez [15] reporting that most respondents were "relatively well informed and progressive in their reported understanding of schizophrenia and its treatment," future stigma-reduction plans can be targeted at known areas of low knowledge and high social distancing because the authors found that knowledge was a central modifiable correlate of stigma. By recognizing the ceiling effect of costly and time-consuming generic awareness-raising crusades, stigma reduction strategies can shift to more focused approaches.

Although generic and targeted awareness-raising campaigns seem to have been effective, family members and particularly people with schizophrenia continue to report experiencing a high level of stigma. Family members and recipients of mental health services reported that social stigma "is the single most important factor undermining their quality of life, and a key barrier to care and treatment compliance" [15]. Future research activities to develop an instrument to capture perceptions of stigma reliably and validly from the viewpoints of family members and people with schizophrenia would offer an important contribution to the field of assessing and responding to the real and perceived social stigma surrounding schizophrenia [15].

After World War II, critical professional attention in schizophrenia research became focused on the family. Behavior, genes, and communication patterns have been examined, assuming that the cause of the disease must lie with the family [14]. In the 1980s, the study of the affects of expressed emotion (EE) within families with schizophrenia became popular

as being a major environmental component in predicting disease outcome [16,17]. This orientation proposes that if a stressful family environment can be modified, patients should experience fewer relapses [18].

It is not useful for family members to be overly negative or critical regarding relatives with schizophrenia. Most family members have learned the delicacy of the self-esteem of loved ones with schizophrenia and strive to relate lovingly and patiently with a positive, encouraging, constructive, and sensitive spirit. Although it is useful to be aware of the consequences our own approach has on our family member, it is equally useful to consider the effect the disease has on our lives and how, over the long-term, aside from being sensitive to striving for a low level of EE with our relative, we can give care in a way that does not compromise our own well-being and that of our own family.

It is important to move beyond the analysis of emotion as it is expressed between us and our mentally ill loved one and to examine experientially the impact of our family's struggles on our lives and in our relationships. As Jones [14] stated, considerable prior research has "been guided by highly ideological concerns that have led to considerable gaps in our understanding of the real experiences of families." To be constructively involved in the life of a person with schizophrenia over the long-term involves establishing the financial, family, and social foundations needed to ensure adequate housing and timely and appropriate services are available to the person with schizophrenia.

Sibling outcomes

In addition to the feelings of isolation, stigma, and secrecy that commonly accompany schizophrenia, mental health professionals and people affected by mental illnesses propose the outcomes of schizophrenia on siblings can be significant. Torrey [19] proposed the impacts on siblings may include:

- Shame and embarrassment
- Anger, jealousy, and resentment
- Depression and guilt
- Pressure to succeed
- Fear of becoming sick
- Forced to play unwanted roles

Other authors of books aimed at supporting families coping with caregiving for the mentally ill echo Torrey's family findings and add that siblings (and offspring) of the mentally ill commonly experience the following [4,5,20]:

- Genetic fears
- A skewed sense of normalcy

Deferred dreams
Decreased pleasure in own successes
Not marrying or not having children
Ongoing grieving
Ambiguity
Fear of the future

Guilt and grieving

Although I have enjoyed an interesting and rewarding career, it has been easy to feel guilty over the gap between my embarrassment of opportunities and Sherry's scarcity of choices [20]. Kübler-Ross' [21] five-stage grieving model (denial, anger, bargaining, depression, and acceptance) offers a framework for grieving. Although useful, this model is more applicable to a death—of a person or of a relationship. People grieving losses related to mental illnesses find they may cycle through all stages at different times and report feelings and experiences not covered in Kübler-Ross' five categories. The standard linear five-phase approach has limited application to the ongoing grief families and people with schizophrenia feel over the loss of dreams for what life could have been like if mental illness had not struck. Families have to adjust continually to grieve the losses this disease constantly imposes on loved ones' lives and to grieve their own losses. Unresolved guilt and grieving can be barriers to establishing relationships between brothers and sisters.

Patterns of reaction

Although many mainstream Hollywood movies, such as *One Flew Over the Cuckoo's Nest* and *Silence of the Lambs*, have portrayed mental illness in its darkest forms, other Hollywood portrayals have played a more positive role in raising awareness of family members' struggles. The movie *A Beautiful Mind* catapulted the schizophrenia movement's efforts to raise awareness of schizophrenia. It has helped explain to friends and extended family members how difficult and confusing it can be to be with someone who is mentally ill. The movie depicts the life of Nobel Prize winner John Nash and won four Academy Awards in 2002: best picture, best director, best screenplay, and best supporting actor [22]. The movie's success in realistically portraying schizophrenia and the challenges the disease brings was no coincidence. Screenwriter Akiva Goldsman is the son of two prominent child psychologists who ran a group home with the mentally ill, and he had real-life experiences with schizophrenia [23].

In 1993, CBS aired *My Sister's Keeper*, a movie based on the book by Margaret Moorman [24]. The movie is based on a true story and is about the ongoing relationship between two sisters, a schizoaffective woman who had been diagnosed as a teenager and her successful sister. The director of

the movie, Ron Lagomarsino, has family members with schizophrenia. *My Sister's Keeper* echoes the 1986 television production of *Promise*, in which the main character takes over the care of his schizophrenic brother after the death of their mother. *Promise* won an Emmy and a Peabody award.

The end result of these Hollywood productions facilitating greater awareness of mental illness and its impacts on the family is not inconsequential. Although the list of realistic and sensitive portrayals of family roles in schizophrenia is not long, these few mainstream North American movies set, according to the National Alliance for the Mentally Ill, “a new standard for the entertainment industry in depicting mental illness” [25]. All three movies mentioned solidly depict the difficulties of being a caregiver for someone with schizophrenia.

Torrey [15] discussed how siblings can be put suddenly into difficult guardian roles. Secunda (both an offspring and a sibling of mentally ill persons) reported that some siblings who do not feel balanced in their role with their ill sibling may fall into one of three forms of relationship with their ill family member: (1) custodian; (2) bystander, or (3) adversary. The categories are not static, and they are not mutually exclusive; a person's roles can be fluid. A sibling may move between these roles before finding a more integrative and sustainable approach to caregiving. Secunda's categories are derived from 75 interviews with family members.

Custodians are ultrasponsible, perhaps having the person who is ill live with them or assuming complete responsibility for them such that they may jeopardize their own health (or that of their families) [26,27]. A larger number of siblings, Secunda [5] reported, are *bystanders*. Out of frustration and no doubt for a variety of other reasons, many siblings are on the sidelines, not engaged actively with their families around the care of the person who is ill. It can be confusing trying to work one's way through the muddle of “madness”: “I think the illness breeds a certain form of manipulation. Some of it is that you know the person is manipulating you and some of it is, you know, they really aren't well and this is their survival skill” [4]. If people do not understand schizophrenia, they may see their sibling's behavior as merely controlling manipulations against their parents or may feel their sibling is lazy because they do not seem to be working toward finding solutions for the challenges in their life. A third role common in family dynamics is that of an *adversary*. This role involves a person not in agreement with the family over caregiving plans or otherwise at odds with the family [4].

In my own experience, I can relate to all three of these roles. At one time, not understanding the complexities of this disease, I wondered why my sister and parents were having so much trouble getting along. In the absence of knowledge, it was easy to be adversarial and think simple solutions would help. For this reason, as noted previously, I assumed I could care for my sister full-time and had her live with me one summer. At that time, I was also feeling guilty and became a custodian. When I crashed out of that role, having had an overwhelming experience resulting in my sister being

institutionalized for a year (offering another opportunity to feel guilty), I slipped into a bystander mode and interacted relatively infrequently with my family. We remained close and communicated regularly over the telephone and during occasional, usually seasonal, visits. I took solace in Oscar Wilde's famous quote, "Happiness is a close knit loving family in a distant city."

Ultimately, none of these roles—custodian, bystander, or adversary—is balanced but nonetheless seem to be common patterns some siblings may experience in seeking sustainable and reasonable involvement in the lives of their loved ones. Developing a reliable instrument to assess sibling patterns and levels of involvement (including "best practices") would advance the schizophrenia movement's effort to reduce the suffering caused by schizophrenia.

Relationship patterns

Secunda [5] found that more siblings of the mentally ill were single compared with the general population. In her interviews, she asked siblings about relationship patterns and developed four categories based on the responses. The categories are similar to relationship patterns reported by addictions counselors [28]:

- Avoidance of relationships
- Incomplete relationships
- Abusive relationships
- Relationships with mentally ill partners

None of these patterns is adaptive or constructive. Siblings and other family members may develop a skewed sense of normalcy in learning to live with crazy behavior. Siblings become accustomed to and consequently have a higher tolerance for deviant behavior. Although this adjustment in what is normal and abnormal behavior may be constructive to some degree in accepting the strangeness of schizophrenia, it also can predispose people to imbalanced or unhealthy relationships outside of the family. In my conversations over the years with other siblings, many people have discussed how the "flashing red lights" that normally appear when meeting someone who may be dangerous, destructive, or hurtful do not appear or flash until much later, when they are already involved in a dysfunctional relationship.

Reporting these tentative interview outcomes and narratives is not to imply that all family members of the mentally ill are in dysfunctional relationships. Perhaps this concept offers a partial explanation, however, as to why so few siblings are involved actively with their ill brothers and sisters—they could be busy with their own (perhaps not psychotic but nonetheless frightening) "demons." When caregiving—giving more than you receive—becomes the norm, it is easy to become involved in imbalanced relationships without realizing the level of inequity.

Alternatively, enjoying a healthy long-term relationship can go a long way toward strengthening an individual's capacity to caregive for an ill sibling. It is important to identify patterns within families and to examine the barriers preventing families from preparing for the future because this lack of planning is jeopardizing the stability and well-being of people with schizophrenia. Given that suicide is such a significant issue in schizophrenia, with half of sufferers attempting suicide at some point and approximately 10% succeeding [29–31], we can save lives if we can work in helping families plan more assertively for what lies ahead.

Studying Secunda's approach to exploring the results schizophrenia has on family members was life-altering for me. Secunda draws on the posttraumatic stress disorder (PTSD) model, developed by Herman [32], which offers a therapeutic approach to experiencing trauma. In a support group/workshop environment, I began discussing my reflections on Secunda's findings with other siblings, and many of us could recognize similarities in our own patterns. We saw how patterns of nonreciprocity in our families sometimes predisposed us for getting into imbalanced friendships, work relationships, and intimate relationships. Not only am I a healthier and happier person for having worked on healing from the distress mental illness brought into my life, but also I have considerably more time and energy to share with Sherry.

Healing from the scars of schizophrenia can strengthen sibling relationships. It can be painful and difficult to deal with the harshness of the darkest hours of mental illness. When an individual is psychotic, particularly if he or she is paranoid, he or she may say or do things that are hurtful. How relationships recover from or if they recover from the damage done during the darkest time of schizophrenia is contingent on numerous variables, such as the quality of the relationship and closeness before the person became ill and the capacities and motivations of both siblings to work together [5].

Providing support, education, and respite is useful because there is considerable chaos in the lives of most families of the mentally ill: "Family members experience varying degrees of grief, denial and bewilderment. The typical family of a mentally ill person is often in chaos" [33]. Peer support provides a forum for sharing and receiving social supports and offers a platform for advocacy.

Acute and posttraumatic stress disorder and caregiving

The World Health Organization (WHO) defines a stressor as an acute or long-lasting event that is of an exceptionally threatening or catastrophic nature, which is likely to cause pervasive distress in almost anyone. Given the high rate of suicide and incarceration of the mentally ill [34,35], families seeking services often are facing a catastrophe. In some instances, although it is rare, family members may be threatened if the person who is ill is actively psychotic within an unstable environment. According to the WHO definition, caregiving for a mentally ill person is a stressor.

The symptoms of acute stress disorder include anxiety, dissociative experiences, and other symptoms. The more serious manifestations of PTSD can involve a person reexperiencing the traumatic event, avoidance and numbing, and increased arousal [36,37]. Although there are many forms of trauma (eg, natural disasters or accidents), the model that is most suitable in caregiving for the mentally ill relates to PTSD relative to individuals who have been victimized. DSM IV lists the consequences of victimization as fear and anxiety; depression; decreased self-esteem or identity problems; and anger, guilt, and shame [36,37]. Negative manifestations of PTSD from victimization are similar to the reported experiences of family members caregiving (or avoiding caregiving, as is the case in many families) for people with schizophrenia.

Rarely, family members are victimized directly by their relative with schizophrenia. More commonly, a family member experiences secondary trauma through the victimization of their mentally ill loved one. Approximately 80% of the mentally ill live in poverty. Many have no housing, and others live in unsafe low-cost rental areas, where their chances of being victimized are higher. The many mentally ill in prisons have a higher chance of being victimized while incarcerated. Experiencing secondarily the victimization of one's family members is traumatic and can have lasting impacts; research indicates higher than average rates of PTSD in first-degree family members whose family members experienced a traumatic event [38,39].

Given the absence of empirical data on patterns of family members of the mentally ill, it is not possible to offer representative quantitative data on relationship patterns. Researching the experiences of family members would be useful in exploring further the connection to the trauma of experiencing, albeit secondarily, the darkest hours of "madness" within our own homes. Although future research into psychological responses of family members would be useful, it is also important to understand qualitatively the experiences and possibly differing and individual responses to the illness of a family member. Rather than a cause-focused sibling exploration, a model that examines the consequences of this disease on brothers and sisters (and offspring and partners) would be beneficial in developing and sustaining support groups such as the Saskatchewan Sibling Connection.

Healing

The emotional burdens and chaos that can result for a family member from a getting a phone call in the middle of the night from a relative in crisis (or a call from police or hospital emergency department staff) are immense. Whether the person decides to respond or not, the fallout and consequences can be dire. Not responding means possibly risking a suicide or some other grim outcome, and responding means at the very least losing sleep for a night and most likely experiencing a serious disruption for the foreseeable

future. Either way, ending up in a crisis situation seems to be a losing proposition. Families can prepare and work at ensuring continuity of care for people who are ill and avoid relapses and crises. There are alternatives to living in (or in fear of) continual chaos. Accepting the diagnosis, the heavily stigmatized label of *schizophrenic*, is a key component of avoiding chaos.

Actively communicating more with my family about real future plans noticeably reduces the stress I feel about the future. It has changed my life to have a clearer understanding of my sister's life and the mental health system and community supports in place for her courageous and ongoing journey. Sherry tells me she is also thankful that we are talking about the future. At the end of the day, how she and I are doing together and how we feel are what matter most. Although the future is still full of ambiguities, we feel more confident in our abilities to be able to work together toward a sustainable future.

Supporting families

Historically the stigma and myths that have surrounded mental illness have isolated families and have been an obstacle to treatment. Many of the infamous and inglorious treatment approaches over the years have had unhelpful and even destructive outcomes: "The history of schizophrenia treatment is unfortunately replete with therapeutic claims for interventions that heightened rather than abated the patient's suffering, augmented rather than reduced the stigma associated with this illness, contracted rather than expanded the patient's abilities and quality of life, and magnified rather than lessened the burden borne by family members" [40].

Typically, much of the information on supporting families is focused on increasing awareness of exactly what mental illness is and how best to support the process of stabilizing the individual and preventing a relapse. Although this basic information is essential during the early years after a diagnosis, there is great merit in moving beyond strategies focused on the person who is ill and concentrating on family members healing from the personal outcomes this illness can have. Individual counseling or support groups can be useful mechanisms for siblings to find pathways to establishing a reasonable plan for the future.

Financial planning

Although counseling and group experiences can offer useful healing for some, a variety of different strategies need to be employed for engaging siblings in future planning. If the parents of the person who is ill have accumulated an estate to pass onto their children, family members would be well advised to seek specific professional advice in their state or province that may relate to their situation [41]. It is crucial to have an appropriate financial plan for the future. Talking about family finances can be a tangible and

practical way to open the ongoing discussion on caregiving and future planning. Families should secure solid legal advice on estate planning and the logistics of leaving an inheritance to an ill family member and of protecting the inheritance of family members who are not ill.

It was not easy for me to approach my father on his finances and future financial plans, but when I did and he forthrightly shared his will and strategy with me, my stress about being overloaded and overburdened in the future financially lessened, and I began to feel more confident about my ability to respond to the uncertainties of tomorrow. It is imperative that families work with lawyers or financial experts who are experienced with current legislation governing family estates and dependent adults. Considerable court time is occupied with protracted litigation among family members whose parents did not make appropriate arrangements in this regard.

In Canada, a nongovernment organization that started in Burnaby, British Columbia, called the Planned Lifetime Advocacy Network helps families with financial and other future planning [42]. Family members with intellectually handicapped children established the organization, and given the high demand for family financial planning, it has expanded to support families of disabled adults [43]. Although mental health practitioners are not financial planners, it is advisable for such practitioners to prompt families to discuss finances. Also, as noted, talking about tangible financial details can open the door to other intangible concerns about the future. Regardless of state-specific or province-specific laws, strategizing as a family to maximize family resources over the long-term is a concrete first step toward a more solid future.

Engaging with the human services policy environment

WHO estimates that two out of five, or 40%, of disabilities are caused by mental disorders, accounting for approximately 12% of the global burden of all diseases [44]. Expenditures for mental health services account for just 1% of overall health expenditures [44]. Worldwide, 40% of countries have no formal mental health policy, and 90% have no adolescent and child services at all [44]. Although not perfect, comparatively the Canadian health system is one of the best in the world. Canadians generally enjoy a high quality of life, and all Canadian jurisdictions provide mental health services of various forms, although programs vary by province [45]. Although the proportion of total health expenditures allocated to mental health services is more than the global rate of 1%, many mental health advocates propose the proportion of expenditures allocated to mental health services is gravely disproportionate relative to overall health and human service spending.

Numerous drivers are straining the existing health care structure in Canada. The combined drivers of (1) demographic changes (the overall aging of the population, the rapid growth rate of Saskatchewan's Aboriginal

peoples), (2) the challenges of recruiting and retaining health care human resources, and (3) higher demands for newer and more costly pharmaceuticals and technologies are necessitating increasingly difficult policy and practice choices [46,47]. One outcome is increasing out-of-pocket costs for a variety of “nonessential” health services, outside the parameters of universally covered hospital and physician services. Increasingly, Canadians are purchasing rather than being provided health and other human services.

Just as judicious financial planning within families is important, working collaboratively as lobbyists for adequate care and protection of the human rights of the mentally ill is increasingly important. Advocating effectively for the inclusion of mental health issues in the future human services system is an important component of building a sustainable future. Mental health services should remain part of the mainstream health system and not be relegated to the sidelines, where programs can be cut or dismantled further at the discretion of local politicians or bureaucrats. Although decentralization, or regionalization, of health services is a common trend in today’s shifting health care system, given the misunderstandings and myths surrounding mental illness, psychological and psychiatric services should remain centralized. Otherwise the risk of further fragmenting an already disjointed system exists. Rural and isolated locations are most at risk in decentralized decision making, in which other priorities (eg, high health needs of an aging population) dominate the policy agenda.

For this reason, WHO cited including primary care with mental health care as its number one health policy recommendation [44]. The other WHO recommendations are in line with our own advocacy goals: ensure a variety of choices of psychotropic medications are available, create intersectoral links, choose mental health strategies that are cost-effective and maximize resource efficiencies, and use community resources to stimulate change [44]. Whether in Canada or the United States, these WHO goals provide a useful framework for sibling strategies and are issues that we seek to advance in our communities.

Pharmaceutical accessibility

In Canada, drug plans and formularies differ by province or territory because health services are the responsibility of provincial governments [45]. In some provinces, newer atypical neuroleptics are not approved for coverage under provincial (or territorial) pharmaceutical plans because the newer drugs invariably are considerably more costly. More detailed economic analysis of the cost benefits of reducing the institutional costs of acute care and supported care by providing access to more expensive pharmaceuticals is necessary. Lobbying efforts by family members for such an economic analysis potentially could benefit ill loved ones. Given the focus on reducing hospital and other forms of institutionalized care and strengthening community care, the analysis of whether or not Canada’s proposed pharmacare system should cover newer high-cost drugs needs to incorporate a cost/

benefit analysis of reduced relapses and an increased quality of life and community participation for people with mental illnesses. Front-line medications are used to minimize the losses associated with heart disease, and so too should better quality products be available to people with neurologic diseases, such as schizophrenia. The chronic consequences of side effects—particularly weight gain and metabolic dysfunctions—are serious.

Although newer medications might epidemiologically help just a small proportion of people who have schizophrenia (a mere fraction of a percent of the population), the life-altering outcomes the right medication can have on a person are worth the effort it takes to bring that new pharmaceutical product to the community. To see the difference the correct medication can make for a person verifies how worthwhile it is to lobby for choices in neuroleptic treatments. It is essential the schizophrenic movement align itself with health economists to counter misunderstandings and misperceptions of approval committees and provide a broader perspective regarding the significance of cost differences between older versus newer drugs.

Intersectoral collaborations and effective interventions

Although the proper form and dosage of antipsychotics can work miracles, individuals with schizophrenia have multiple other needs, beyond lessening the positive and negative symptoms of the disease. Just as optimizing the potential synergy between psychopharmaceutical and psychotherapeutic interventions can improve outcomes, strengthening the capacities for collaborating between sectors strengthens the potential for people with mental illnesses to contribute in their communities to their highest capacities. Opportunities for labor, education, and decent housing and a justice system sensitive to the complex needs of the seriously mentally ill would go a long way toward improving the functioning of people with schizophrenia. Better integration of existing services could reduce redundancies and maximize the outcomes of expenditures among various existing departments and community organizations.

Work

It is encouraging that in schools and workplaces we have progressed to the point where wheelchair accessibility is commonly accepted and most often mandatory. It would be equally encouraging if we could allocate the human resources and increase corporate inclusiveness to create flexible and suitable employment and education opportunities for the mentally ill. Over the years, some of my friends with schizophrenia have shared experiences of being enrolled in education programs with criteria that were not achievable given inflexibilities with timelines and attendance. If we can expand our hallways to include wheelchairs, we can expand our minds and hearts to include subsidized, supported, and flexible work arrangements for the mentally ill to

contribute in workplaces. It is important that the many sectors intersecting with people who have schizophrenia work together to maximize the opportunities and reduce the limitations of stigma in communities.

Housing

The availability of affordable and decent housing for low-income people in Canada has decreased substantially [48–50]. The mentally ill have been among the hardest hit by the shifts in the housing sector: “A housing crisis exists because many severely ill patients are unable to meet or maintain the housing providers’ requirements” [33]. People with mental illnesses report having an increasingly difficult time obtaining and sustaining housing [51]. Before succeeding in an educational or work venture, people’s housing crises require resolution, which is another example of the importance of intersectoral collaborations. Many siblings I know had their relative live with them at some point and found, as I did, that living together is not a reasonable or sustainable option. It is fundamentally important to the stability of our loved ones that adequate housing be available. Through skillful advocacy, my parents secured a placement for my sister in an approved home, staffed 24 hours and offering supported care, where she has been stable for several years. We are fortunate she is in a stable situation and recognize the benefits to our entire family of her secure housing situation. We are definitely concerned about how we would cope if Sherry were not in a long-term stable and supported home.

The British Columbia Schizophrenia Society proposes a systemic commitment and approach to housing that is system-wide and not just a targeted program [33]. A segregated program is too easy to cut, and the Society maintains, “ample resources have not been spent on focus groups, reports and studies. Too many people with severe mental illness have no decent place to live. It is time resources were allocated for real solutions to the housing crisis in mental health” [33].

Health Services

A policy opportunity for integrative programming lies within the existing health and social services systems in which addictions programs are developed separately from services for the mentally ill. A vast proportion of the mentally ill are dual diagnosed. Comorbidity complicates treatment. Some existing addictions treatment programs, particularly residential programs, require patients to cease taking all substances, which, for someone who is mentally ill, involves risking a relapse. It is neither reasonable nor advisable for someone with schizophrenia to stop taking his or her medicines, even if only for a short time. The gaps in intersectoral collaboration of existing addictions programs results in individuals with multiple needs being without appropriate treatment programs. Equally as important as the collaboration

between addictions professionals and psychiatric workers is a better integration of suicide prevention and crisis intervention programs with existing mental health programs [44]. Strengthening these community-based services reduces the stress and isolation siblings experience when seeking to be involved constructively in their loved ones' lives.

Health Human Resources

Professional caregivers need to be supported in working with family members. The fee-for-service model and current workload allocation in salaried positions (eg, within psychiatric hospitals) are a disincentive to working with other family members. Anecdotally, professionals have told me how they and colleagues will “scatter” (ie, make themselves scarce) when family members come to visit. It is not out of a lack of caring that workers have to draw boundaries. Rather, regardless of how therapeutically beneficial time spent with family members may be, the time spent with family is rarely recognized within either the fee-for-service billing system of psychiatrists or in the salaried work allocations of other staff. The result is that the family therapy that workers provide becomes a benevolent gesture, akin to a form of extracurricular or volunteer activity, rather than an institutionally expected, supported, or even recognized aspect of the health care professions. Restructuring the billing system and workload designation to provide incentives for authentically supporting family members would go a long way toward redressing policy and practice imbalances that impede family development of long-term plans for the stable and continuous care of people with serious mental illnesses. Recognizing and responding to the needs of the entire family would be useful for families and for the health care professions involved. Bringing the family more into the institutionalized relationship between patient and healer in mental health care could offer numerous benefits.

Community Development and Support

Building capacities within communities to work proactively in providing mental health services is the most efficient and sustainable approach toward the future. It is important to foster community leadership and let a solid analysis of the problems guide expenditure decisions in ways that foster sustainable community development. Resource allocation priorities should be set based on a community development model so that we are actively caring rather than passively mending for our most vulnerable citizens, the severely mentally ill [44].

Family members who have not had the chance or inclination to reflect on the effect the disease has had on their lives may do well to see a professional counselor privately or to be involved with a support group, such as the “caring and sharing” gatherings available across Canada through local chapters

of the Schizophrenia Society. Some family members prefer one-on-one support, available through staff or volunteers of provincial Chapter offices. Local offices could support siblings better by having sibling “mentors” available to talk about experiences and share their stories.

In addition to local action, we also have to think globally and align with families and professionals in other countries so as to maximize the synergy of champions around the globe. By working collaboratively, the worldwide schizophrenia movement can continue to influence public health policies and foster the support networks and effective therapeutic alliance. The World Fellowship for Schizophrenia and Allied Disorders [52] supports fostering policies and practices that move families, the mental health field, and general communities from “passive minding to active caring” for people with schizophrenia [44].

Am I my sister’s keeper?

Often I ask myself whether or not I am my sister’s keeper. My obligations are dissimilar to those of my parents, but she is my only sister. Although her illness has not been easy for her or for the rest of our family, she is an outstanding person, and my life is richer for her being in it. In many ways, it has brought our family closer because I think it is unlikely my parents and I, in the absence these pressing issues, would speak so frankly about the future. Although none of us is sure what tomorrow brings, at least we are talking about the uncertainties and are clear on what we are certain about. Through working with other families, I have come to appreciate the greatest gift the family can give is a noncritical, loving supportive relationship that helps the individual to meet the challenges that lay ahead.

I am inspired continuously by Sherry and am working with her to create the best future possible for us. It is in part because of her continual courage that I look for the energy and patience to be involved in her life. I believe that if the situation were reversed, she would be working with me to ensure I did not end up being homeless and dying in some inner-city back alley. Luckily I am sane (stressed perhaps, but sane) and so, yes, to some degree I am my sister’s keeper. As a family member from another province put it: “None of you would abandon your family member if they had a physical disability. Please don’t ask us to abandon our loved ones because they’ve got this illness” [33]. Ultimately, Sherry is her own keeper, however, and my active way of caring focuses on helping us both prepare for our future journey together.

Summary

Few families seem to be preparing adequately for the future with respect to financial planning or caregiving responsibilities. The consequences

of schizophrenia on siblings and sibling relationships can be significant. Exploring how the chaos and confusion that typically accompanies the onset of the illness may have adversely affected family members and family relationships can offer an opportunity to build proactive partnerships toward future planning for continuity of care for the mentally ill. The Schizophrenia Society of Saskatchewan facilitates family involvement in fostering a sibling support strategy focused on the specific issues faced by siblings of people with schizophrenia. Support groups and the provision of concrete family financial and caregiving planning are tangible ways siblings can prepare better for the future. Strengthening lobbying capacities is also important to advocate partnerships between integrative community-based, client-centered services and family members of the severely mentally ill.

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References

- [1] Starce MM, Maj M, Pirozzi R. A family study of DSM-III-R schizoaffective disorder, depressive type, compared with schizophrenia and psychotic and nonpsychotic major depression. *Am J Psychiatry* 1991;148:612–6.
- [2] Egan MF, Hyde TM, Gscheidle T, et al. Relative risk of neurological signs in siblings of patients with schizophrenia. *Am J Psychiatry* 2001;158:1827–34.
- [3] Staal WG, Hulschoff Pol HE, Schnack HG, et al. Structural brain abnormalities in patients with schizophrenia and their healthy siblings. *Am J Psychiatry* 2000;157:416–21.
- [4] Karp D. *The burden of sympathy: how families cope with mental illness*. New York: Oxford University Press; 2001.
- [5] Secunda V. *When madness comes home: help and hope for the children, siblings, and partners of the mentally ill*. New York: Hyperion; 1997.
- [6] Woolis R. *When someone you love has a mental illness: a handbook for family, friends and caregivers*. New York: Putnam's; 1992.
- [7] Ismail B, Cantor-Graae E, McNeil TF. Neurological abnormalities in schizophrenic patients and their siblings. *Am J Psychiatry* 1998;155:84–9.
- [8] Kendler KS, MacLean CJ, O'Neill FA, et al. Evidence for a schizophrenia vulnerably locus on chromosome 8p in the Irish study of high-density schizophrenia families. *Am J Psychiatry* 1996;153:1534–40.

- [9] Thaker G, Adami H, Lahti A, et al. Psychiatric illnesses in families of subjects with schizophrenia spectrum personality disorders: high morbidity risks for unspecified functional psychoses and schizophrenia. *Am J Psychiatry* 1993;150:66–71.
- [10] Schizophrenia Society of Canada. Schizophrenia: youth's greatest disabler. Toronto: Schizophrenia Society of Canada; 2001.
- [11] Forsyth P. Who will be there? Families worry what will happen to ill children when parents are gone. *Schizophrenia Digest* 2001;8:16–19.
- [12] Goldberg J. Coping with cognitive impairments. Presented at the Schizophrenia Society of Canada's National Conference, Moving Forward Together. Toronto, Ontario, Canada, June; 2001. p. 1–3.
- [13] Pallanti S, Quercioli L, Pazzagli A. Relapse in young paranoid schizophrenic patients: a prospective study of stressful life events, P300 measures, and coping. *Am J Psychiatry* 1997;154:792–8.
- [14] Jones WJ. Myths, madness and the family: the impact of mental illness on families. UK: Palgrave; New York, 2002.
- [15] Stuart H, Arboleda-Florez J. Community attitudes toward people with schizophrenia. *Can J Psychiatry* 2001;46:245–52.
- [16] Falloon I, Boyd J, McGill C, et al. Family management in the prevention of exacerbations of schizophrenia. *N Engl J Med* 1982;306:1437–40.
- [17] Falloon I, Boyd J, McGill C. Family care for schizophrenia. New York: Guilford Press; 1984.
- [18] Hooley JM. Expressed emotion and psychiatric relapse: from empirical data to clinical practice. *Behav Ther* 1998;29:631–46.
- [19] Torrey F. Surviving schizophrenia: a manual for families, consumers and providers. New York: HarperCollins; 1995.
- [20] Woolis R. When someone you love has a mental illness: a handbook for family, friends and, caregivers. New York: Putnam's; 1992.
- [21] Kübler-Ross E. On death and dying. Touchstone; New York, 1997.
- [22] And the Oscar goes to... The Regina Leader Post. March 25, 2002. p. A7.
- [23] Available at: <http://www.hollywood.com/celebs/detail/celeb/188248>.
- [24] Moorman M. My sister's keeper: learning to cope with a sibling's mental illness. New York: Viking Penguin; 1993.
- [25] Available at: <http://www.nami.org/pressroom/mysisterskeeper.html>.
- [26] Lamb W. I know this much is true. New York: HarperCollins; 1998.
- [27] Silverman DC. Psychosocial impact of HIV-related caregiving on health providers: a review and recommendations for the role of psychiatry. *Am J Psychiatry* 1993;150:705–12.
- [28] Wilson Schaefer A. When society becomes an addict. New York: Harper & Row Publishers; 1987.
- [29] Radomsky ED, Haas GL, Mann JJ, et al. Suicidal behavior in patients with schizophrenia and other psychotic disorders. *Am J Psychiatry* 1999;156:1590–5.
- [30] Harkavy-Friedman JM, Restifo K, Malaspina D, et al. Suicidal behavior in schizophrenia: characteristics of individuals who had and had not attempted suicide. *Am J Psychiatry* 1999;156:1276–8.
- [31] Caldwell CG, Gottesman II. Schizophrenics kill themselves too: a review of risk factors for suicide. *Schizophr Bull* 1990;16:571–89.
- [32] Herman J. Trauma and recovery: the aftermath of violence from domestic abuse to political terror. New York: Basic Books; 1997.
- [33] British Columbia Schizophrenia Society. Our abandoned citizens: policies for change, Vancouver, British Columbia Schizophrenia Society; 2000.
- [34] Ogloff J. The identification and treatment of mental illness in jails: challenges and strategies. In: Schizophrenia Update. Proceedings from Riverview Hospital's Annual Conference on Schizophrenia, 2001, Riverview Hospital, Port Coquitlam, BC, Canada. p. 1–22.
- [35] Ogloff J, Roesch R, Hart SD. Mental health services in jails and prisons: legal, clinical, and policy issues. *Law Psychol Rev* 1994;18:109–36.

- [36] Morgan CA, Hazlett G, Wang S. Symptoms of dissociation in humans experiencing acute, uncontrollable stress: a prospective investigation. *Am J Psychiatry* 2001;158:1239–47.
- [37] Classen C, Koopman C, Hales R. Acute stress disorder as a predictor of posttraumatic stress symptoms. *Am J Psychiatry* 1998;155:620–4.
- [38] Amick-McMullan A, Kilpatrick DC. Homicide as a risk factor for PTSD among surviving family members. *Behav Modif* 1991;15:545–59.
- [39] Brent DA, Moritz G. Long-term impact of exposure to suicide: a three-year controlled follow-up. *J Am Acad Child Adolesc Psychiatry* 1996;35:646–53.
- [40] Seeman MV. Schizophrenia: unravelling treatment. *Can J Psychiatry* 2002;47:11.
- [41] Schizophrenia Society of Saskatchewan. Wills, trusts and trustees. In: Guidelines for estate planning and wills for parents of persons with psychiatric disabilities. Regina, Canada: Schizophrenia Society of Saskatchewan; 1993. p. 49–64.
- [42] Etmanski A. Safe and secure: clarifying your vision. In: Six steps to creating a personal future plan for people with disabilities. Burnaby: Planned Lifetime Advocacy Network (PLAN); 1996. p. 11–23.
- [43] Available at: <http://www.nami.org/books/LifePlanningWorkbook.htm>.
- [44] World Health Organization. World health report 2001: mental health, new understanding, new hope. Geneva: World Health Organization; 2001.
- [45] Thompson K, Passmore R. Health services program comparison. In: Passmore R, Fritz W, Yuske M, editors. Interprovincial comparisons: Provincial/territorial health services and selected data. Regina: Saskatchewan Health; 1998. p. 88–98.
- [46] Commission on the Future of Health Care in Canada. Interim report. Saskatoon: Commission on the Future of Health Care in Canada; 2002.
- [47] Government of Saskatchewan. The action plan for Saskatchewan health care. Regina: Saskatchewan Health; 2001.
- [48] Rude D, Thompson K. Left in the cold: women, health and the demise of social housing policies (35). Winnipeg: Prairie Women's Health Centre of Excellence; 2001.
- [49] Chisholm S. No place to stay: social policy reform in Canada and its impact on affordable housing. *Canadian Housing* 1999;16:14–7.
- [50] Geller G, Kowalchuk J. Supportive housing needs of women with mental health issues. Project Reports, Social Administration Research Unit, Faculty of Social Work, University of Regina, Regina, 2000.
- [51] Available at: <http://www.world-schizophrenia.org/>.
- [52] Tedeschi RG, Park CL, Calhoun LG. Posttraumatic growth: positive changes in the aftermath of crisis. Mahwah, NJ: Lawrence Erlbaum & Associates; 1998.