Surviving the Tornado of Mental Illness: Psychiatric Survivors' Experiences of Getting, Losing, and Keeping Housing

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This qualitative study explored experiences of psychiatric consumer-survivors related to housing. Nine focus groups involving 90 people were conducted in urban and rural areas in South-Western Ontario. A set of open-ended questions was used. Many participants described a devastating experience of losing much of what was important to them and going through a long arduous process to rebuild their lives. Group discussions were audiotaped and transcribed. Individual and team analyses of the transcripts revealed that psychiatric survivors experienced three levels of upheaval, loss, and destruction, similar to the effects of a tornado: losing ground, struggling to survive, and gaining stability. Within each of these levels, five major themes were identified: living in fear, losing control of basic human rights, attempting to hold onto and create relationships, identifying supports and seeking services, and obtaining personal space and place. A caring community response, including adequate housing, income support, and community care, can help people rebuild their lives. (*Psychiatric Services* 57:558–562, 2006)

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The recent trend in deinstitutionalization from hospital to community for psychiatric consumer-survivors has frequently led to housing problems. Psychiatric survivors are consistently found to be overrepresented in homeless populations (1–3). Housing stability has become an important concern for this population.

The Canadian Mortgage and Housing Corporation (4) examined the issue of housing stability for consumer-survivors and emphasized the importance of preference in determining an individual's ability to maintain stable housing. The authors noted that the process of making a house a home is based on interactions between three key factors: person, support, and housing. For a housing situation to be stable, an individual should receive appropriate support within a physical and social housing environment suited to the individual's characteristics, goals, preferences, strengths, and needs. The authors noted that housing stability is often defined as duration of stay. They suggested that an appropriate measure of stability should include consideration of the quality or desirability of housing mobility rather than simply the quantity of moves.

Research from New Zealand has expanded on the concept of designing housing for consumer-survivors to facilitate housing stability (5). This work focused on the issue of sustainability in the context of mental health and housing as an attribute of the wider environment rather than of a particular house. A "sustainability framework" was developed that details the array of supports and resources necessary to maintain independent living. Access to four categories of resources is necessary for true sustainability. First, a supportive regulatory environment is needed, which implies well-enforced statutory government frameworks that apply to safeguarding human rights; combating discrimination; and regulating the labor market, building codes, and housing standards. Second, material resources must be available, including adequate and suitable housing to choose from, income to pay for it, and access to basic necessities. Third, service resources are necessary, including clinical services, housing facilitation services, and personal support services tailored to individuals' needs. Fourth, social resources are needed, including community supports, groups, families, and cultural and social networks.

The issue of housing preference has been explored in the literature as

a means of addressing the housing needs of persons with mental illnesses. This research has consistently found that independent living is preferred (6,7). Unfortunately, psychiatric consumer-survivors often face many obstacles to obtaining and keeping independent housing.

A review of existing research on supported and supportive housing undertaken by the Cochrane Review (8) found a lack of conclusive evidence about the effectiveness of supportive housing as opposed to supported housing options. The authors concluded that further research is required in this area. A cautionary note was injected by O'Malley and Croucher (9), who indicated that assuming that patients will progress from higher to lower levels of supported accommodation over time may be marginalizing the needs of a group of individuals with particularly challenging behavior who require long-term, permanent accommodation with higher levels of support.

In summary, although housing issues are known to be of concern for psychiatric survivors, the literature has many gaps. Studies have focused on issues such as homelessness, housing stability, and housing preference. Subjective experiences related to housing remain largely unexplored. The purpose of this investigation was to explore experiences of psychiatric consumer-survivors in relation to housing and identify potential solutions to difficulties encountered by this population. The study used descriptive qualitative methods and focus groups. Ethics approval was granted through the University of Western Ontario, and data were compiled in July and August 2002.

Focus groups

Participants were recruited through posters and word of mouth. Posters were placed in a variety of locations in order to recruit individuals living in a range of housing types, including shelters, group homes, transitional housing programs, and public housing units. Posters were also sent to community mental health agencies, a consumer-survivor self-help organization, and the public library. Posters indicated that we were interested in recruiting people with a history of mental illness to discuss issues related to housing and mental health and gave the time and location of the next group. Letters of information, which outlined the project in more detail, were available below the poster and were also distributed and reviewed before beginning each group.

Groups were held in a spectrum of community locations, including shelters, group homes, community agencies, and drop-in centers. Staff members at the group locations were also helpful in using word of mouth to encourage people to attend. Food, usually pizza, was available at each of the group discussions to encourage and acknowledge attendance.

The metaphor of a tornado was used to capture the experiences related to housing and illness that consumer-survivors described.

Nine focus groups, which averaged 75 minutes in length, were conducted in both urban and rural areas in South-Western Ontario over two months, with five to 13 participants per group. The total sample included 51 females and 39 males. Five groups included both men and women. Two groups were for women only, and two were for men only. Participants lived in shelters, group homes, supported apartments, and independent housing. No demographic information was obtained, but field notes indicated that participants ranged in age from late teens to late sixties, but the majority appeared to be in their forties and fifties. The groups were predominantly Caucasian, with some representation from members of minority groups, including Asian, African Canadian, and First Nations/Aboriginal.

Research team members led the groups. A common set of open-ended research questions and prompts were used as guides for all groups. Questions included: What is your current housing like? What kind of housing would you prefer? What was the best place you ever lived? What made it so good? What stops you from being in that ideal place now? The questions were used to stimulate conversation. Issues raised in individual groups were explored in more detail.

Group discussions were audiotaped and transcribed verbatim. Two note takers were present during each group to record field notes. Field notes were completed during and immediately after each group. They included a description of the setting and participants, as well as general impressions. The notes were added to the transcripts and included in the analysis.

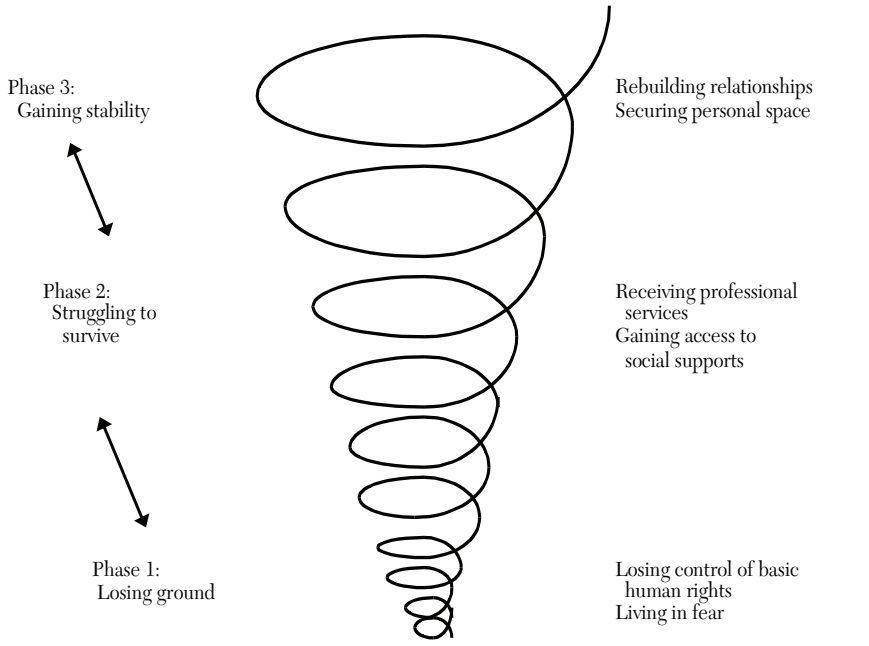
A metaphor, themes, and phases

The study used an ethnographic method of analysis (10). A full ethnography would require a longer period of observation. A broad approach was desired to help us understand the patterns related to housing and mental health in the social and cultural contexts of the participants across multiple settings. The ethnographic analysis first identified and listed descriptors and then developed them into patterns. Patterns were then synthesized to obtain broad themes. Themes were then tested by reviewing them against raw data.

Data were initially analyzed independently by each research team member. Team members then met on three different occasions to compare and further develop the identified themes. A matrix was used to assist in the development of identified patterns—for example, living with fear or losing control—into larger themes. Team members who made slight revisions to the interpretation of themes and patterns then reviewed the matrix and transcripts.

Figure 1

Three overlapping phases within the tornado of mental illness



On the basis of the analysis of the focus group data, the team members proposed a metaphor of a tornado to describe the upheaval and loss encountered by the study participants (Figure 1). Few phenomena can form as quickly as a tornado and create such devastation in such a short time and in such a random way. Although the probability of actually being touched by a tornado is quite small, and surviving a tornado is likely, it is nonetheless a substantive force that cannot be ignored. Tornadoes not only enter lives unexpectedly, they rip them apart and scatter the accumulated possessions of a lifetime haphazardly, often across great distances and usually without warning.

Participants saw their experiences related to housing as part of broader experiences related to supports. In other words, obtaining and maintaining housing were related to obtaining and maintaining a broad base of supports, ranging from assistance with psychiatric symptoms to income supports.

Three overlapping phases within the tornado of mental illness were proposed: losing ground, struggling to survive, and gaining stability (Figure 1). Depending on certain environmental forces, psychiatric survivors moved between and among the three phases. Five major themes were also identified within the phases. Living in fear and losing control of basic human rights were dominant themes in the losing-ground phase, and gaining access to social supports and receiving professional services were the most common themes within the struggling-to-survive phase. Finally, the themes of securing personal space and rebuilding relationships were identified in the gaining-stability phase.

In November 2003 the findings from the data analysis were presented to a group of 75 key stakeholders, including consumer-survivors, researchers, and members of community agencies. They were explicitly asked for oral or written feedback about the analysis and the metaphor used. Feedback was received from six consumers (four oral and two written), and all their feedback supported the analysis and metaphor. Supportive written feedback was also received from two community mental health service providers. Written feedback tended to be brief—for example, "Tornado a great metaphor."

Phase 1: losing ground

Losing ground was the first and most destructive phase of the tornado identified in the study findings. Metaphorically speaking, the tornado is at its greatest strength in this phase, uprooting people and causing the most damage, perhaps even death. Indeed, some individuals with mental illness may not survive these "killer" tornados, especially if they have experienced consistent loss and destruction as a result of poor housing conditions.

The words of two participants illustrate this destructiveness. "Some of the homes have been condemned. . . . Four of them, I had to leave because they burnt right down. I lost everything." "So I had to leave everything, and that isn't the first time. I had lost a lot of belongings, seven times to fire and five times to just up and leaving, and carrying whatever I could. So I am getting pretty tired of it."

Loss of current living arrangements also frequently occurred when individuals needed to be hospitalized because of their mental illness. As one woman explained, "They made me give up my apartment. . . . I left everything behind—my couch, my TV, everything, my fish tank, everything. I left it all behind because they said I wasn't well enough to go back, I wasn't able to look after myself."

Living in fear was the dominant theme in this phase. Participants were fearful of many things; they were afraid of being hurt and of losing their lives or their possessions. One young man remarked, "There has been a lot of violence in my building . . . . One guy here tells me he is going to kill me daily." A woman commented that she did not want to live in a house—even one with affordable rent—where there may be people who would harm her or her family: "Even if I were to get housing and they said, 'Oh, you could pay $97 a month for a one bedroom,' I wouldn't take it—considering what is out there. I mean, the guy next door may be a pyromaniac, and the other one might be a pedophile for all I know."

Women who lived in shelters and other living arrangements that housed both men and women shared additional concerns: "Him and me were in

[a facility] together. He attempted to rape me on the ground. . . . Went back there this year, after finally a year and a half, only to find out that this guy's been let off."

Others agreed that women and men living together constituted a risk to women's safety. One man stated, "If there is a female . . . three rooms over, hey, you're going to have like ten dogs [males] over, right! So to put it more plainly, it would just be a festival. It wouldn't work. . . . It would be trouble."

Losing control of basic human rights was the second predominant theme in this phase. It was apparent that persons with mental illnesses felt deprived of adequate income, which led to inadequate food and housing. One woman explained, "The comfort allowance [personal needs allowance] is the same today as it was ten, 12 years ago in 1990. It is like the government has something against people with mental illness. We are being punished and held down financially. If you have a mental illness, they say, 'Here's this,' and shove you into a corner. . . . I have nothing."

The cramped conditions under which many people with mental illness are expected to live are sometimes deplorable. Residents frequently must share limited toilet facilities. A man living in a shelter described his experience: "You are living with, and sleeping with, 25 other guys, and you gotta deal with their noise when they come in and out of the room. And as far as the rest goes, I mean we're all men and we all do what men do, so if you gotta do it, you do it."

Other participants reported that they were treated "like children" who had no choice but to comply with the rules. One man explained, "You have to beg for a drink when you want one. I find I get thirsty a lot. You're not supposed to be around the kitchen. You get yelled at."

Phase 2: struggling to survive

Struggling to survive was the second phase of the tornado identified in the study findings. As people started to pick up the pieces from the destruction caused by the tornado, they still struggled with meeting their basic needs. As one woman explained, "I was in an apartment of my own, and I was trying to cope with it, but I didn't have any support. They just dumped me here."

For others, energy was expended toward gaining access to social supports. Such supports were seen as critical to maintaining more independence in housing. One man explained how he needed to use a variety of supports to survive, and yet at times these social programs were inadequate to meet his basic needs: "I am sorry, but a can of beans and a little bit like that once a month is not going to go anywhere. . . and the food bank is here but it is only going to feed you for two days, and when you have no money, what do you do for the other 28 days?"

"I left everything behind —my couch, my TV, my fish tank, everything. I left it all behind because they said I wasn't well enough to go back."

Other participants attended church programs to acquire adequate food and shelter. "In the wintertime, they have suppers at the church over there. I go for a free meal. Meals are usually on at some of these churches all around the city."

In addition to providing meals, some of the churches and housing providers offered professional counseling services. Many participants also relied heavily on the services of health professionals to survive this phase of the tornado. However, many spoke of the difficulties they experienced in gaining access to and receiving professional services in a timely fashion. If their symptoms are not treated, they fear losing their housing.

Phase 3: gaining stability

Gaining stability is the final phase of the tornado. Participants in this phase reported that they were beginning to rebuild their lives. Because most of their basic physical and medical needs were met, they were free to concentrate on securing personal space and rebuilding relationships. Some of the participants spoke about the importance of having their own place and of setting down roots again: "I am in my fifth home. . . . But this one I know that I can stay for two years and I can finally go to a permanent home after that. So I know I'll finally be able to have a home that I can call home for quite a while."

Others commented on the differences between their current living arrangements and their previous types of housing. Most notably, participants mentioned that they appreciated living in a "nice" neighborhood, being "allowed" to have pets, and having their own bathroom and kitchen appliances. One woman aptly described this aspect of gaining stability: "In this house I used to live in, there were 20 people in the same house. So, now there is eight, and there's a huge difference. . . . There is more space to yourself."

The final theme, building relationships, was most evident in this last phase of the tornado. In the early phases, relationships were usually tenuous or destructive. Participants who were gaining stability spoke about the importance of relationships and how strong relationships with friends or family were key to their health and well-being. One participant described how sharing meals with someone led to a strong friendship: "I was on the main floor and I had a lady friend on the other floor, and we switched back and forth for meals. One night I would cook, the next night she would cook and she'd supply the vegetables, or if she was coming to my place I'd supply the meat. . . . We are still good buddies

even though I have been out of there all these years. And she is out of there too, and we still communicate."

Questions and implications

A question to consider is, What is the tornado? Is the tornado the experience of mental illness or the experience of society's response to mental illness? The participants' descriptions would suggest the latter. The loss and destruction experienced were not linked to the experience of symptoms, such as depression or hallucinations. Rather, the loss and destruction were related to the loss of home, possessions, relationships, and human dignity. The consequences of such loss after experiencing a mental illness would seem to have more to do with society's response to the illness, rather than the illness per se.

When an actual tornado strikes, disaster relief is usually immediate. Government aid is available, and community organizations from near and far move quickly to provide tangible supports. What happens when psychiatric survivors experience their more personal tornadoes? It may be that the initial tornado is visible only to family and close friends, who, because of their proximity, feel the strong winds of disaster. Perhaps these forces are invisible to those more distant. Or perhaps the disaster is visible from a distance but simply does not provoke a need to respond in others.

Certainly government aid is not quick to arrive, particularly in Ontario, Canada. At the time of data collection, there had been no increase in community mental health funding or disability income support for over a decade despite inflation and continued policies of deinstitutionalization. Since then small increases have been made. Individuals who receive assistance from the Ontario Disability Support Program actually risk having the housing portion of the assistance cut during a hospitalization on the assumption that because they are hospitalized rental support is not required. Few landlords cease to charge rent during a hospitalization. Therefore, as some of our participants described, people with mental illnesses can lose not only their apartment but also their furniture and the family album. Other participants in our study lost their belongings when the treatment team believed that they could not live independently because of their illness. They were discharged to a group living situation that could not accommodate many of their possessions, including furniture and pets.

The issues described by participants suggest some strategies. As participants initially lost ground, the issues of living in fear and losing control over their basic human rights surfaced. Such feelings were primarily related to being forced into unsafe or otherwise inappropriate housing. Participants struggled to survive by gaining access to social supports and obtaining professional services. Timely availability of such supports and services might assist consumer-survivors to move more quickly to the phase of gaining stability. Stability was maintained by securing personal space and rebuilding relationships. These consumers described accommodation, which includes personal space and control, as critical in rebuilding their lives. Relationships can be facilitated through consistent professional relationships. In addition, support for peer-support and consumer-survivor organizations can give back a sense of belonging. Many participants described the role of churches in facilitating their recovery through tangible supports that went beyond traditional spiritual support.

The metaphor of a tornado was used to capture the experiences related to housing and illness that consumer-survivors described. Many described a devastating experience of losing much of what was important to them and going through a long arduous process to rebuild their lives after the devastation. Health care providers and policy decision makers need to be aware of the losses that are not simply a result of the symptoms of mental illness but more the result of response to the illness. A caring community response, including adequate housing, adequate income support, and available community care, may help people rebuild their lives.

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