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HOW DO WE RECOVER? AN ANALYSIS OF PSYCHIATRIC SURVIVOR ORAL HISTORIES



ORYX COHEN, M.P.A., has emerged as a leader in the international consumer/survivor/ex-patient (c/s/x) movement. Currently he is the career initiatives coordinator for the Western Massachusetts Training Consortium. He oversees and supports c/s/x-led microenterprises and self-employment projects. Oryx is the cofounder of Freedom Center, the Pioneer

Valley's only peer-run support/activist organization. Freedom Center's purpose is to empower and support people with psychiatric labels while challenging oppressive mental health policies and practices. He serves on several boards and committees nationally and regionally, including the National Association for Rights Protection and Advocacy (NARPA) and Windhorse Associates. He volunteered for several years with MindFreedom International, directing its Oral History Project, which involved collecting and documenting c/s/x stories of abuse, empowerment, recovery, and resistance in the mental health system.

Summary

This article analyzes interview and survey data collected during the course of the MindFreedom International Oral History Project from June 1 through September 1, 2001. The purpose of the MindFreedom Oral History Project was to gather stories of experiences in the mental health system from the psychiatric survivor or ex-patient perspective. Thirty-six people participated in the study, most of who consider themselves "psychiatric survivors." Qualitative and quantitative analysis reveals four major themes emerging from these histories: trauma, social control, internalized oppression, and recovery. The focus of this article is on the theme of recovery. Participants demonstrated resiliency and a strong ability to "recover." No "magic bullet" was found to work for all participants' recovery process; instead, participants used a variety of self-designed strategies to recapture their once broken lives.

Keywords: *psychiatric survivor; mental health; recovery; wellness; oral history*

INTRODUCTION

The "madman," as defined by others, is part of society's cultural heritage. Whether "madness" is explained by religious authorities (i.e., as demonic possession), by secular authorities (as disturbance of the public order), or by medical authorities (as "mental illness"), the mad themselves have remained largely voiceless. (Chamberlin, 1990, p. 323)

The perspective of ex-patients is usually left out of history books and the psychiatric literature, leaving explanations of the human psyche and evaluations of treatment regimes to the "experts." Relying on psychiatrists to critique mental hospitals or therapy techniques is akin to making teachers the sole evaluators of their classrooms. This study allows psychiatric survivors to describe in their own words their experiences with psychiatry. Because most of the study's participants have more or less "recovered," their stories can tell us much about what is effective and what can be improved in today's mental health system.

The Consumer / Survivor / Ex-Patient Movement

Led by those who refer to themselves variously as "ex-patients," "consumers," "ex-psychiatric inmates," and "psychiatric survivors," the consumer/survivor/ex-patient movement has gained momentum in the past 30 years. The following passage from Mead and Copeland (2000) illustrates a common experience for consumers/survivors/ex-patients attempting to recover a sense of wellness:

Recovery has only recently become a word used in relation to the experience of psychiatric symptoms. Those of us who experience psychiatric symptoms are commonly told that these symptoms are incurable, that we will have to live with them for the rest of our lives, that the medications, if they (health care professionals) can find the right ones or the right combination, may help, and that we will always have to take the medications. Many of us have even been told that these symptoms will worsen as we get older. Nothing about recovery was ever mentioned. Nothing about hope. Nothing about anything we can do to help ourselves. Nothing about empowerment. Nothing about wellness. (p. 315)

Most consumers/survivors/ex-patients involved in the modern movement reject the "medical model" of biopsychiatry and argue that "mental illnesses" are an emotional/behavioral/biological/spiritual manifestation of a complex interplay of social, emotional, and cultural stressors (Bassman, 2001; Breggin, 1991, 2003; Chamberlin, 1990; Fisher, 1998, 2003; Fisher & Ahern, 1999; McLean, 1995; Neugeboren, 1999). We view "mental illnesses" as temporary crises as opposed to physical diseases. We stress empowerment and recovery versus maintenance, hope versus resignation (Bassman, 2001; Fisher, 1998, 2003).

Evidence for Recovery

Under the medical model, in which "mental illnesses" are viewed as "brain diseases," complete recovery is not a possibility. However, research and experience show that many of us labeled as "severely mentally ill" do recover over time, especially when involved in programs that emphasize hope, optimism, and potential (Fisher, 2003; Fisher & Ahern, 1999). Courtney Harding's longitudinal study that tracked more than 1,300 subjects originally diagnosed with schizophrenia during several decades found that one half to two thirds "had achieved considerable improvement or recovered" (Harding, Brooks, Ashikaga, Strauss, & Breier, 1987, p. 727).

Other studies have compared traditional hospital environments to nontraditional community programs such as residential lodges and clubhouse settings. None of these studies has found traditional models to be more effective. In fact, the bulk of this research points to the superiority of nontraditional alternatives, especially in terms of cost and the promotion of independent living (Mowbray & Freddolino, 1986).

Several studies have compared medications to various talking therapies. However, these studies usually focus on improvement or reduction in symptoms as opposed to recovery. Psychiatrists and psychologists usually find middle ground and suggest that the best solution lies in some sort of combination of medications and psychotherapy.

However, there are limitations to these studies. Breggin (1991) found that there was strong investigator bias in studies of antidepressant medications. Some researchers consistently find positive results, whereas other researchers have found that anti-

depressants barely outperform placebos if they outperform them at all (Breggin, 1991, 2003).

The recent push to focus on recovery has led to researchers attempting to operationalize the recovery process. Spaniol (1999) defined recovery as a process of adjusting one's attitudes, feelings, perceptions, beliefs, roles, and goals to achieve outcomes or achievements such as developing a support network, living in stable housing, working in a challenging job, contributing to the community, and having limited or no impairment in functioning. One commonality found throughout the literature on recovery is the importance of empowerment in the recovery process (Bassman, 2001; Chamberlin, 1990, 1997; Fisher, 1998; McLean, 1995; Reidy, 1994; Rogers, Chamberlin, Ellison, & Crean, 1997).

Recently, leaders in the consumer/survivor movement have attempted to define empowerment so that it will have more meaning in the mental health field. These researchers find that defining empowerment as it relates to self-help programs can help evaluate these programs and guide future programs. Some of the important elements of empowerment emphasized in these studies are having decision-making power, access to information and resources, and a range of options from which to choose; using assertiveness; having hope for the future; unlearning conditioning; learning how to express anger; affecting change in one's life and the community; learning important skills; improving one's self-image; and overcoming stigma (Chamberlin, 1997). Rogers et al. (1997) found that these elements can be broken down further into three major factors that constitute empowerment: self-esteem/self-efficacy, actual power, and community activism.

The recent focus on empowerment has led to the formation of numerous self-help groups and consumer-run alternatives. The study reported here attempted to clarify notions of "self-help" and "empowerment" and their role in the recovery process.

What determines whether someone will recover or not? Is it possible to identify commonalities in the recovery process, or is recovery strictly an idiosyncratic phenomenon? What are these people recovering from? What are the policy implications? Few studies have focused on the process of recovery from "severe mental illness." The present study attempted to approach some of these questions by analyzing stories of recovery. In doing this, the study gives voice to those who consider themselves survivors.

METHOD

This article analyzes interview and survey data that the researcher collected while directing the MindFreedom International Oral History Project from June 1 through September 1, 2001. The purpose of the MindFreedom Oral History Project was to gather stories of experiences in the mental health system from the psychiatric survivor or ex-patient perspective.

Participants

Thirty-six people participated in the study, most of whom consider themselves psychiatric survivors. Largely because of issues of stigma, this population is difficult to locate. Thus, I used purposive snowball sampling to gather participants. Contacts I knew in the psychiatric survivor movement referred me to other psychiatric survivors, who referred me to their contacts and so on, until my sample had "snowballed" to an adequate size. The segment of this population that is easiest to find are those people who are open about their histories and are affiliated with advocacy groups and civil rights organizations like MindFreedom. In fact, all of the referrals for the current study came from MindFreedom and organizations that sponsor MindFreedom.

Participant Demographics

General demographic characteristics of the 36 participants are listed in Table 1.

From this table, it becomes clear that most of the study's participants are older, White, and well educated. Eighty-one percent of the participants were older than 40 at the time of the study, 86% are White, and only 1 participant does not have at least some college experience. In fact, 33% of the participants have at least some graduate school experience. Furthermore, as can be seen in Table 2, most of the participants work full-time and make a decent income.

Sixty-three percent of the participants worked full-time and made more than \$20,000, with 37% making more than \$30,000.¹

In analyzing the demographic data, it becomes clear that most of the psychiatric survivors included in the study blend well with

TABLE 1: General Demographic Characteristics by Age (%)

Age ^b	Gender		Race			Education Level ^a				
	Male (n = 20)	Female (n = 16)	White (n = 31)	Mixed (n = 5)	HS (n = 1)	SC (n = 10)	C (n = 13)	G (n = 12)	Total (N = 36)	
20-30	5.56	2.78	5.56	2.78	0.00	0.00	0.00	8.33	8.33	
30-40	5.56	5.56	8.33	2.78	0.00	5.56	2.78	2.78	11.11	
40-50	22.22	19.44	38.89	2.78	0.00	16.67	19.44	5.56	41.67	
50+	22.22	16.67	33.33	5.56	2.78	5.56	13.89	16.67	38.89	
Total	55.56	44.44	86.11	13.89	2.78	27.78	36.11	33.33	100.00	

a. HS = high school or less; SC = some college; C = college graduate; G = graduate school and beyond.

b. Age of participants as of August 1, 2001.

TABLE 2: Work Status by Income

Work Status	Income in Thousands				
	< 5 (n = 2)	5-10 (n = 6)	10-20 (n = 5)	20-30 (n = 9)	> 30 (n = 13)
Full-time	0.00	5.71	5.71	25.71	25.71
Part-time (PT)	0.00	2.86	0.00	0.00	5.71
PT/disability	0.00	5.71	5.71	0.00	0.00
UE/disability	5.71	2.86	2.86	0.00	0.00
Retired	0.00	0.00	0.00	0.00	5.71
Total	5.71	17.14	14.29	25.71	37.14
					Total (N = 35)

NOTE: UE = unemployed.

the dominant social order. Most of the participants are White, most work, and most are well educated and therefore, assumedly, fairly intelligent. These data are somewhat surprising because they are in direct contrast to other studies that have found "mental illness" disproportionately affects those who are poor and those who are homeless (General Accounting Office, 2000). However, the participant demographics make sense in that almost all of the participants have significantly recovered and many have distanced themselves from the mental health system entirely. Having an education, being White, and having an income may have helped these people on their road to recovery, because they were already accepted on some social dimensions. Another factor that deserves mention is that minority survivors, although out there, were simply difficult to recruit, which is not an uncommon problem among studies of this type (Cannon, Higginbotham, & Leung, 1991).

Because the bulk of the research took place in Oregon and California, 69% of the study's participants were from the West Coast. All but 1 of the face-to-face interviews were with people who lived in Oregon's Willamette Valley or the Bay area of California; the exception was a woman from Boston, Massachusetts, whom I interviewed at a rally in Vancouver, British Columbia. However, the e-mail survey did generate at least some response from all four of the country's major regions as well as from other countries. Two people from Canada and 1 person from Germany are included in the present study. In terms of marital status, 47% of the participants were single, 26% were married, 21% divorced, and 6% were widowed. Almost a quarter (24%) of the participants had children.

Recruitment Methods

In utilizing snowball sampling, three major strategies were used. First, MindFreedom included a question on its membership survey asking, "Would you be willing to share your story with an MindFreedom intern?" Second, several announcements publicizing the project were made on MindFreedom listservs that include thousands of members. Third, MindFreedom staff recruited project participants at MindFreedom events and visits to local mental health organizations. Potential participants were told that the study's purpose was to gather stories of survival, recovery, empowerment, and self-determination from the perspective of the psychiatric survivor or ex-patient. Hundreds of people responded want-

ing to participate. Because MindFreedom lacked the resources to interview all interested persons, the organization prioritized those individuals who were willing to attach their name to their story and have it published on MindFreedom's Web site. In the end, 22 individuals were interviewed face-to-face, 14 surveys were received (these included 2 people who were also interviewed), and 4 open-ended written submissions were received (including 2 people who also completed the surveys).

Two complementary methods were used in this study: semi-structured interviews and surveys.

Interviews

The study included 22 semistructured interviews designed to allow participants to discuss their experiences with the mental health system in an open-ended manner. The first step in the interview process was gathering basic demographic information and a rough profile through MindFreedom's fieldwork data sheet. The fieldwork data sheet was adopted from New York State's Oral History Project and included brief questions about psychiatric labels received, psychiatric drugs prescribed, other mental health experiences, and recovery methods used. After gathering general information through the fieldwork data sheet, interviewees were given a list of preview questions that included two main questions, and several other subquestions to reflect on before the interview. Directly preceding the interview, participants read and signed an informed consent and a release form.

During the interview itself, the interviewer first asked two main questions: (a) Can you describe the process you went through in recovering from periods of intense emotional distress? and (b) Can you describe how you overcame human rights violations in the mental health system? This second question was developed after it became clear that participants were recovering not only from intense emotional distress or "mental illness" but also abuses in the mental health system. Interviewees were ensured that they could share as much or as little of their story as they felt comfortable. The main questions were purposely open ended to allow interviewees to describe their experiences in their own words, without substantial interruption. Because one of the study's major purposes was to explore recovery dimensions, many of which have been identified in previous research, certain probing questions

were used later in the conversation to direct the interviews. However, because the interviews focused on areas important to the participants, not all of the probing questions were used during every interview.

The interviewer had a very active role during these interviews. A crucial part of the interview was to establish rapport and make interviewees feel comfortable talking about difficult and sometimes painful experiences. Because the interviewees were psychiatric survivors themselves, they disclosed and shared some of their history with the interviewees. The fact that the interviewees shared many of the same experiences as the interviewees undoubtedly led to more authentic answers. Of course, although the interviewees did disclose some of their experiences, recognizing the purpose of the study, they kept the focus on the interviewees and their stories.

All of the interviews were videotaped and audiotaped and then transcribed. This study includes analysis of the transcribed interviews.

Surveys

An e-mail survey, composed of questions similar to those used in the interviews, was mailed to several hundred individuals affiliated with MindFreedom. These were extensive, open-ended surveys, 14 of which were completed and returned during the course of the project. As with the interviews, the surveys included questions that attempted to address all possible dimensions of the recovery process.

Before implementing the final version, a pilot survey was issued to several MindFreedom members via listservs. As a result of the pilot test, confusing questions were clarified and several questions were added, modified, or eliminated completely.

Written Submissions

Four free-form written submissions were included in this study's analysis. The written accounts were received in response to SCI's call for psychiatric survivor histories. These autobiographical accounts ranged from 1,000 to 1,500 words and addressed many of the same interview and survey questions.

Data Analysis

The interviews, surveys, and written submissions were analyzed for themes. First, the researchers extracted 26 subthemes, such as the "importance of support" and "abuse of power relationships" from the raw data. We then grouped the subthemes into four larger categories that capture most of these stories' important lessons: (a) trauma, (b) social control, (c) internalized oppression, and (d) recovery. The focus of this article is on the last of these themes: recovery.

RECOVERY

Most of the study's participants described their recoveries from "mental illness" and/or abuses they encountered in the mental health system—such as forced drugging, electroshock, restraints, seclusion, and verbal abuse—as a process. A few participants felt as though there was nothing to recover from, and some felt that they had made "complete" recoveries. As discussed previously, the literature suggests that the recovery process leads to outcomes such as developing a support network, living in stable housing, working in a challenging job, contributing to the community, and having limited or no impairment in functioning (Spaniol, 1999). In this sense, the majority of the participants have made significant recoveries. Most participants are working, many have found support within the consumer/survivor/ex-patient movement or elsewhere, many think of themselves as activists and most have found effective ways to cope with life events and have little or no problem with psychiatric "symptoms."

Table 3 shows that most of the participants have been out of the hospital for more than 5 years after being diagnosed with "severe mental illnesses" such as schizophrenia, bipolar, and depression.

Most of the participants (70%) were diagnosed with schizophrenia (either by itself or in combination with other disorders), a "disorder" that is considered especially resistant to treatment (Fisher, 1998). About half of the participants were diagnosed with more than one disorder. The average participant was hospitalized six times. Despite all of this and despite many of the problems that diagnosis itself can cause (Honos-Webb & Leitner, 2001), the par-

TABLE 3: Diagnosis by Years Out of Hospital

Diagnosis/Label	Years Out of Hospital		Total (N = 33)
	1-5 (n = 7)	> 5 (n = 26)	
Schizophrenia	3.03	27.27	30.30
Bipolar	3.03	12.12	15.15
Depression	3.03	0.00	3.03
Schizophrenia/depression	0.00	6.06	6.06
Schizophrenia/bipolar	0.00	6.06	6.06
Schizophrenia/multiple	9.09	18.18	27.27
Multiple ^a	3.03	6.06	9.09
Other	0.00	3.03	3.03
Total	21.21	78.79	100.00

a. Multiple diagnoses, not including schizophrenia.

participants have made significant recoveries. How were they able to do it?

No Magic Bullet:

Multiple Recovery Methods Worked

Figure 1 shows that participants attributed their recoveries and improved sense of well-being to a number of important "recovery methods."

Figure 1 indicates participants' most common recovery strategy was the support of friends and family (at 72%). Social activism, exercise, and one-on-one therapy were also commonly reported (69%, 61%, and 58%, respectively). Group therapy and psychiatric drugs were only reported by 25% of the participants.

Given the difficulties that participants experienced with psychiatric drugs, it is not surprising that only one fourth felt that they assisted in their recovery process. This also happens to be the number of people currently taking medications, and with just two exceptions, the people who felt medications helped were those who were currently taking them. Most of the participants who are using psychiatric drugs use only one or two drugs, and many express a desire to eventually get off the "meds." For example, after finding a place that would listen to his "drug cocktail" complaints, Tony L. is now on just one medication of his choosing, Wellbutrin.

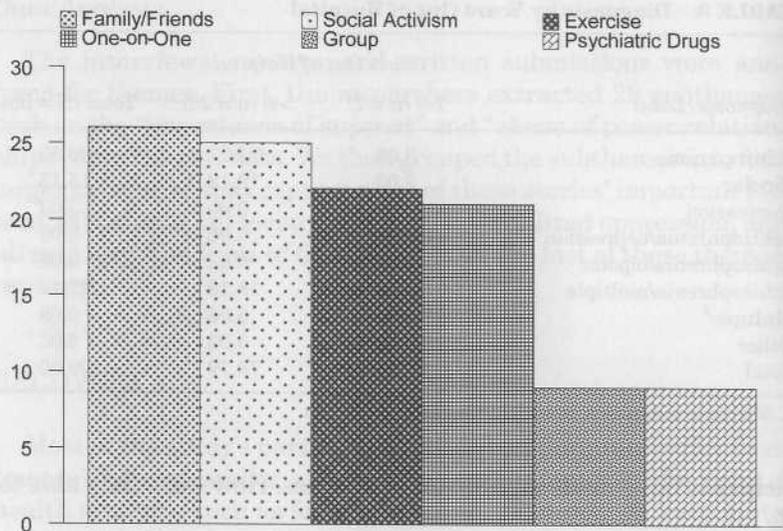


Figure 1 Participants Used Many Recovery Methods (N = 36)

Viveca W., a 47-year-old office assistant, describes her feelings about being on Prozac.

Prozac helped me return to a place of no depression. Before taking Prozac, I was always slightly depressed. I will say that if I could find a way of getting off the drugs without becoming depressed or manic, I would do it.

Although she does feel that Prozac has helped her, Viveca wants to find a way to get off of it. Viveca's experience also shows that different people can react in very different ways to the same drug, as other participants described how they felt Prozac triggered manic episodes and suicidal thoughts.

As Figure 1 indicates, it wasn't one "magic bullet" that "cured" these people. Instead, a combination of methods and circumstances allowed participants to improve their sense of well-being. Along with the importance of having support, participants indicated the importance of strategies like diet, reading literature, and spirituality.² Perhaps most important, for the majority of participants there came a time when it "all clicked," when they realized that nobody was going to recover for them, they were going to have to find a way to do it themselves.

One-on-One Therapy

Although most of the study's participants tended to reject institutional treatments such as psychiatric drugs and group therapy, it is interesting that many reported one-on-one therapy as a recovery method. Most of these people had both "good" and "bad" therapists, but usually "one good therapist" stood out as especially helpful. Participants described these therapists—whether they were psychiatrists, psychologists, or other professionals—as people who were perceptive, who listened, and who treated them with respect. Susie I. describes her relationship with her favorite therapist.

I was really worried when I switched from Network to Unity because I had one of the best therapists I have ever had at Network and I didn't want to lose that. This therapist was really honest and easy to talk to. In the way she would help me, it was more me discovering what was going on than her saying, "Well, this is what it is."

Carol P. had a good experience with an intern on the psychiatric ward.

I remember one intern in particular who really listened to me. I guess she hadn't been there forever and wasn't burned out yet. Well, she gave me a sense of hope and made me feel like I really wasn't much different than she or anybody else.

This interaction stuck with Carol and eventually she was able to regain control of her life. Many of the participants recalled meaningful interactions with therapists or friends that they could fall back on and that continued to give them strength.

Empowerment

Self-help was actually the most common recovery method reported, as 94% of the participants indicated that they used this strategy. Self-help is not included in Figure 1 because in this study, self-help encompasses multiple recovery methods, which may include traditional self-help groups and other strategies such as diet and meditation. The prevalence of self-help indicates the value that participants placed on feeling empowered to make their own decisions.

Participants' experiences with empowerment reflect all three components of empowerment identified by Rogers et al. (1997):

self-esteem/self-efficacy, actual power, and community activism. To get out of the hospital and start over, the participants developed newer and more positive conceptions of themselves and their abilities to solve problems.

Jody H. talks about how she took a proactive stance and started feeling human again.

If there was a good thing to come out of [the physical abuse in the hospital], at least that abuse created a fighter out of me—I will never take abuse again from this system of coercion and dependency. So I didn't win my rights—I stood up and demanded them. For awhile the system had convinced me that I wasn't fully human and didn't deserve any rights. Well, I learned how to use the Internet 2 years ago at the library and suddenly found that there were other people who had gone through similar things, who were also abused and ostracized. Here were some people who listened to me and actually understood when I talked. I started feeling like a human being again.

After nearly being beaten to death by hospital staff, Jody decided it was time to take action. This action led to her finding people who validated her experience and helped to improve her damaged sense of self.

Mike H. discusses how actions like Jody's can have actual power, leading to real changes.

In 1987 I started to prove the doubters wrong. I was elected the first president of the Board of Directors of Mind and Power, Inc., which I believe was the first totally consumer-run agency in Oregon. At that point, I decided for the first time in my life that, rather than letting the mental health system dictate my life choices for me, I was going to make my own choices about my treatment and how I would conduct life. When I did that, personal power started coming into my life. From 1987 through 1997, I was only hospitalized 3 times. Prior to that, I was hospitalized 17 times. Now, you can do the math, but my life was getting a lot better since I decided that I was going to take care of myself and make my own decisions.

Like many of the other participants, Mike's change in thinking endured over time, creating a positive cycle of change. As Mike felt better about himself, it also affected how other people viewed him. Having more respect and self-confidence, Mike had a chance to realize some of his career aspirations. After a long, hard road, Mike became director of the Oregon Consumer Technical Alliance

(OCTA), the largest consumer/survivor/ex-patient-run agency in Oregon. Having this respected title afforded Mike even more "actual power" to help people who are currently struggling to find their way.

As shown in Figure 1, 69% of the participants reported social activism as a recovery method. Participants such as Mike are now working to make the system better and to educate the public about mental health issues.

Carol P. spoke about her role as an activist.

To me it is about truth and ensuring that the public and the mental health system know the truth. And the truth is, you can't heal me without my cooperation, you cannot. There's no such thing as forced healing. We have to be active partners. That to me is what social action is about. It's sometimes about confronting this giant—it may be the drug companies, public opinion, the legislature—these huge, powerful images, and confronting them with the truth. It also means that your voice has to be heard. You have to be loud sometimes. I think it's really important to be loud and at the same time make sense and tell the truth.

Carol describes her worst time as when she just accepted her diagnosis and everything the doctors told her. Many of the other participants also felt that standing up for themselves, being "difficult" in essence, helped them break away and establish self-sufficiency. Kris Y. explains how this type of attitude helped her.

I think the main thing that was most helpful to me was that I never really accepted the diagnosis. They diagnosed me, but I never thought I was mentally ill or that I had schizophrenia or had anything. I really rejected the drugs totally.

She felt that having this type of attitude might have prevented more hospitalizations. Kris went on to describe how she got involved in peer counseling, which helped her personal development. Along with being empowered, participants found that finding some type of support network was crucial to their recovery process.

Importance of Support

Figure 1 shows that 72% of the participants reported family and/or friends as instrumental in their recoveries. In fact, having a supportive family member or friend can sometimes mean the dif-

ference in getting out of the hospital, an important step on the road to recovery.

David O., the 45-year-old executive director of MindFreedom International, remembers how he got out of McLean Hospital in Boston.

I found out that even a few empowered peers supporting each other could make a huge difference in my life. During my last stay in McLean, Mental Patient Liberation Front (MPLF) activists helped me by complaining to the facility. A MPLF activist dictated over the phone to me the proper legal letter that I would need to try to get out. Through a Haldol haze, I meticulously printed out the letter and filed it. I found out later that the authorities reacted by contacting my parents, asking them to either commit me, seek guardianship, or dissuade me from doing this. My mother told them, "If our David wants to try freedom, we support him."

Because David had the support of his parents and his MPLF friends, he was able to avoid additional time in the hospital.

Unfortunately, for people like Tony L., who lack an active support network, their path to recovery can be a bit rockier (Fisher, 2003). Tony explains what it can be like for people who lack support.

One very important thing that I really want to focus on is that these experiences can vary dramatically, depending on whether or not you have an outside support system. If you have somebody fighting in the outside world for you—for example, family—that's the most important thing, and some of these things may not happen. A lot of them are going to happen anyway, but at least you have somebody out there, a life preserver. In my case, my parents had passed away. I had no further family, my wife had passed away. I had nobody out there whatsoever to fight for me, and that's the case with a lot of consumers. . . . You're totally powerless, and that's the time when the person can turn on you the worst because they perceive you in two ways. One, you're a random factor who can go out and do anything. Two, without a support system, they pretty much can control your life. If they make a mistake, well, who's going to worry? Heck, I could have died!

Luckily, after being homeless for a brief time, Tony was finally able to find some support at a consumer-run agency in Portland, Oregon.

Pat R. describes the importance of finding peer support.

My peers and friends in support groups did understand, and they never tried to "treat" me. Instead, they gave me love, understanding, kindness, and support. I built upon my experiences in the support groups and started to heal.

Pat, Jody, Tony, and many other participants felt that finding peer support was crucial in large part because those who went through similar experiences were able to validate their experiences (Bassman, 2001). In the system, the participants were all told that they were "crazy," and many felt like their thoughts and feelings no longer mattered or counted. Thus, finding support and validation among their peers was integral to improving their well-being.

CONCLUSION: POLICY IMPLICATIONS

A common theme in the interviews was that people did not get "better" or "recover" until they took control of their own "treatment," whether it was meditation, exercise, peer support, or psychiatric drugs. This idea has powerful implications for policies such as Involuntary Outpatient Commitment (IOC) and the Program for Assertive Community Treatment (PACT), which both severely limit people's right to self-determination. It also suggests that policies that encourage self-determination and support the use of holistic alternatives should be supported.

Toward Progressive Mental Health Policy

The study's participants have demonstrated that complete recovery from "severe mental illness" is possible. Most of the participants have returned to work, are "productive" citizens, and have found effective ways to maintain their sense of well-being. It is interesting that most of the participants have accomplished this without the use of psychiatric drugs. In fact, all of the participants, even those currently taking medications, described the adverse effects of these drugs, as well as other treatments, in detail. All of this suggests that the medical model may not be working and that policies that reflect a more holistic conception of "mental illness" should be supported. In fact, research has indicated that alterna-

tive therapies focusing on empowerment and recovery compare favorably to traditional approaches.

In 1971, an alternative to psychiatric hospitalization called the Soteria house was systematically compared to traditional inpatient facilities. The Soteria house was totally voluntary (including medications), peer support and self-determination were encouraged, and the primary task of staff members was to put themselves in the client's shoes: to understand the immediate circumstances and relevant background that led to the crisis. After 2 years, the clients of the original Soteria house were working at significantly higher occupation levels, were living more independently or with peers, and had fewer rehospitalizations than those treated in traditional settings (Mosher, 1999). The vast majority of these individuals accomplished this without the use of medication. Since that time, several other programs have incorporated many of the same philosophies as the original Soteria house.

In terms of evaluation, the Soteria house and its spin-offs have fared quite well. Studies of Soteria-model alternatives generally find that they have as good or better outcomes than traditional programs at significantly less cost. A Soteria spin-off, the McAuliffe house, produced similar clinical results as psychiatric hospitals at 40% less cost. In fact, a review of studies on alternatives found that 19 of 20 studies reported that alternative treatments were as, or more, effective than hospital care at 43% less cost (Mosher, 1999).

The consumer/survivor community endorses these types of programs because they support an individual's right to take responsibility for his or her course of treatment and recovery. Despite this endorsement and despite clinical success, Soteria-model programs have generated little political and financial support. Thus, there seems to be a gap between available evidence and clinical practice (Mosher, 1999). Often, these programs are funded as "pilot" projects, demonstrate initial success, and then are not re-funded (Mosher, 1999). For example, the original Soteria house lost its funding source after 5 years, even after demonstrating positive outcomes. One reason for this is programs that do not require the use of medication have a more difficult time getting past Institutional Review Boards that are firmly entrenched in the medical model (Mosher, 1999). However, although there are substantial barriers, some consumer/survivor advocates have found success.

For example, consumer/survivor groups in California blocked impending IOC legislation and were able to pass a bill that stresses the use of voluntary services (Oaks, 2000).

The study's participants have demonstrated that there is no magic bullet that works for all people who experience severe emotional distress, altered states, or "mental illness." This suggests that policies should be enacted that support and fund alternatives such as peer-run programs, acupuncture, massage therapy, and yoga. For instance, currently Medicaid and Medicare waivers do not cover peer-run programs, a policy that could be changed (National Council on Disability, 2000).

Supporting alternatives may also require stricter oversight of managed care organizations (MCOs) and parity of insurance (National Council on Disability, 2000). Massachusetts and several other states are contracting with private MCOs that operate for-profit, capitated, closed-network systems. Thus, financial considerations are emphasized over clinical outcomes, which has led to a reliance on medication prescriptions and cutting therapy down to 15 minutes per week medication maintenance sessions (National Council on Disability, 2000). As discussed, the study's participants reported that establishing a bond with their therapist was important, if not crucial, to making strides in their recovery. Limiting both the time and content of therapy sessions makes it less likely that people will be able to find that "one good therapist" who really helps. Currently, states offer little or no oversight of MCOs (National Council on Disability, 2000). Perhaps states should install stricter evaluation procedures to ensure that MCOs are meeting not only the needs of providers but also those of the people they serve.

Many alternative treatments, such as acupuncture, are now covered by insurance for physical illnesses. However, these same treatments are not covered for mental disabilities, even though many consumers/survivors, including those in this study, have found these alternatives to be healing. Establishing parity in insurance for those labeled with psychiatric disabilities is another way to provide better access to alternative therapies.

Because those labeled with psychiatric disabilities are over-represented by the poor and the homeless, reforming social welfare policy could be an indirect way of assisting this population. Obviously, not having access to affordable housing, basic medical care,

and meaningful work can make it more difficult to be mentally healthy. In fact, a recent University of Pennsylvania study found that providing supported housing to a group of homeless individuals in New York city was cost effective, reducing state psychiatric hospital costs by \$8,260 and inpatient Medicaid costs by \$3,787 for each supported-housing unit (Bernstein, 2001). Thus, providing housing was able to keep many of these people out of the hospital, improving their lives as well as saving taxpayer dollars.

As deinstitutionalization continues, providing affordable housing is also a way to help integrate marginalized groups such as the "mentally ill" into local neighborhoods. Unfortunately, myths such as the "violent mental patient" make it less likely that communities will truly embrace this population with open arms. Hopefully, as states begin to implement their Olmstead plans (which require maximizing interaction between those with and without disabilities), communities will find that many of these stereotypes are unfounded and will recognize their own capacity to care for people experiencing problems in living.

NOTES

1. Although higher income categories could have been included, I was more interested in assessing whether participants had sufficient income to comfortably take care of themselves, as "mental illness" affects lower-income groups disproportionately. Only 2 of those making \$30,000 or more were making more than \$50,000 per year, a lawyer and a retired chemical engineer.

2. These were not included in Figure 1 because of space considerations.

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CLIENT PERSPECTIVES ON WHAT CONTRIBUTES TO SYMPTOM RELIEF IN PSYCHOTHERAPY: A QUALITATIVE OUTCOME STUDY



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Summary

Assessing psychotherapy outcome with posttherapy questionnaires and self-report instruments does not adequately capture the richness and complexity of change during psychotherapy and relies too heavily on quantitative analysis. This qualitative study explored the lived experience of symptom relief in psychotherapy as perceived by client participants and treats their subjective accounts as credible data. The scientific phenomenological method developed by A. Giorgi was used to conduct in-depth interviews with 3 participants who experienced symptom relief during the course of psychotherapy.

Keywords: *outcome research; psychotherapy research; psychotherapy outcomes; qualitative research; phenomenology*