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CULTURAL CASE STUDY

Culture, Stress and Recovery from Schizophrenia: Lessons from the Field for Global Mental Health

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Abstract This cultural case study investigates one U.S. psychosocial rehabilitation organization's (Horizons) attempt to implement the recovery philosophy of the U.S. Recovery Movement and offers lessons from this local attempt that may inform global mental health care reform. Horizons' "recovery-oriented" initiatives unwittingly mobilized stressful North American discourses of valued citizenship. At times, efforts to "empower" people diagnosed with schizophrenia to become esteemed self-made citizens generated *more* stressful sociocultural conditions for people whose daily lives were typically remarkably stressful. A recovery-oriented mental health system must account for people diagnosed with schizophrenia's sensitivity to stress and offer consumers contextually relevant coping mechanisms. Any attempt to export U.S. mental health care practices to the rest of the world must acknowledge that (1) sociocultural conditions affect schizophrenia outcomes; (2) schizophrenia outcomes are already better in the developing world than in the United States; and (3) much of what leads to "better" outcomes in the developing world may rely on the availability of locally relevant techniques to address stress.

Keywords Schizophrenia · Recovery · Psychosocial rehabilitation · Anthropology · Mental health

Introduction

Schizophrenia affects more than 25 million people worldwide. The World Health Organization's (WHO) recent "Gap Action Programme" promotes "adequate global mental health" for this population, signaled by "a state of well-being in

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which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community" (WHO 2009). This prescription for mental health echoes the U.S. Recovery Movement's definition of "recovery":

> Recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges … to reestablish a new and valued sense of integrity and purpose … to live, work, and love in a community in which one makes a significant contribution. (Ridgway et al. 2002, p. 5)

To provide the world with such "adequate mental health," the WHO program asks stakeholders to "scale up" funding and make psychopharmaceuticals and "recovery-oriented" psychosocial rehabilitation (PSR) interventions available to people with schizophrenia around the globe (Lancet Global Mental Health Group 2007).

Using new recovery-oriented PSR services for "empowerment" and "recovery," I found, was profoundly challenging for one group of "consumers" of mental health services in the urban United States. How were North American notions of "empowerment" understood by staff and consumers and used to promote recovery in this context? How did empowerment techniques help or hinder healing from schizophrenia? A grounded examination of the foundations of current U.S.-based PSR recovery-oriented practices and the ways consumers and providers of PSR services experience them should precede their exportation.

"Recovery" from Schizophrenia

In the absence of a biomedical "cure," many North Americans do not associate "schizophrenia" with "recovery." Kraepelin (1919, pp. 74–75) first described schizophrenia as *dementia praecox* when he demarcated patients exhibiting "chronic deterioration" resulting in "emotional dullness, failure of mental activities, loss of mastery over volition, of endeavor and ability for independent action." People diagnosed with schizophrenia may also experience auditory or visual hallucinations, delusions, bizarre behavior, strange posturing, an inability to interpret communications and a lack of insight into self or others (APA 2000). Active symptoms negatively affect one's cognition, emotions, behavior and quality of life (APA 2000). Barrett (1998) depicted the "modern" Australian "schizophrenic" as "on the outer edge of personhood, trapped between the poles of sickness and health in anticipation of a return to the community of the healthy that is not forthcoming." The *Oxford Textbook of Psychopathology* (Millon et al. 1999, p. 277) suggests, "A substantial proportion of the homeless, populating the streets of urban areas, living under bridges, in cardboard boxes, or in subway tunnels, are also schizophrenic."

Landmark empirical studies in the 1980s (DeSisto et al. 1995; Harding et al. 1987; Strauss et al. 1985) indicated that one-third of people diagnosed with schizophrenia might "recover" completely and another third might experience "partial recovery" with basic psychosocial interventions. These studies challenged the conventional psychiatric assumption of a chronically deteriorating course for people diagnosed with schizophrenia (Andreasen 1997). Patients considered to be "in recovery" scored $\leq$4 on the Brief Psychiatric Rating Scale (Overall and Gorham 1962) and their "social functioning" was comparable to what may have been expected before illness onset (Liberman et al. 2002; Liberman and Kopelowicz 2005).

"Recovery stories," or first-person narratives of the recovery process, provide subjective evidence for recovery from schizophrenia (Bassman 2001; Beers 1960 [1908]; Deegan 1996b; Fekete 2004; Fisher and Torbert 1995; Henderson 2004; Nudel 2009; Saks 2007; Steele and Berman 2001; Tsai 2002; Walsh 1996). Fascinating archives of recovery stories are available at the MindFreedom Web site (MindFreedom 2009) and Web sites where "patients" share information, such as www.schizophrenia.com.

Evidence from around the world also indicates that people can recover from schizophrenia (Calabrese and Corrigan 2005). People diagnosed with schizophrenia in "developing" countries (e.g., Mauritius, Colombia, Nigeria, and India) experience more short- and long-term recovery outcomes than people in Europe and the US (Bhugra 2006; Cohen et al. 2007; Hopper 2008; Hopper and Wanderling 2000, p. 836; Issac et al. 2007; Jablensky et al. 1992; Kulhara and Chakrabarti 2001; Luhrmann 2007; Mueser and McGurk 2004; Murphy and Raman 1971; Patel et al. 2006). This axiom is robustly confirmed by three decades of World Health Organization schizophrenia outcomes studies including follow-up studies of 2–5 years at 30 research sites in 19 countries (Harrison et al. 2001; Hopper 2008; Hopper and Wanderling 2000; Jablensky et al. 1992; WHO 1973, 1979). As Hopper (2008) explained, there is a "relatively constant … odds of recovery ratio of roughly 1.5 favoring the non-industrial group." The best outcomes group was located in Chennai, India, where a remarkable two-thirds of study participants remained symptom-free at 10 and 30 years after first contact (Thara 2004; Thara and Eaton 1996; Thara et al. 2007).

Developing countries may provide a therapeutic context for recovery despite minimal treatment resources (Bresnahan et al. 2003, p. 29; Hopper and Wanderling 2000). In turn, the U.S. mental health system may incorporate "a substantial list of psychosocial artifacts that create chronicity, over and above illness factors" which have "contributed a large segment of patients for whom chronicity could have been avoided" (1987, p. 432). This paper describes how the PSR organization Horizons tried to implement a "culture of recovery" to replace a "culture of chronicity," and the effects this effort had on Horizons' staff and the "members" they serve.

The Emerging Recovery Philosophy in North American Mental Health Care

Since the 1970s, consumers, family members and concerned care providers have formed a patchwork Recovery Movement to reform the U.S. mental health care system. In 1961, President Kennedy signed legislation releasing asylum-based mental health patients and providing them with "community support services" (CSSs) (Grob 1994). CSSs evolved into the PSR model by the 1990s (Felix 1964; Foley 1975; Grob 1994; Stroul 1986; Turner and TenHoor 1978). The PSR model used “case managers” to address the “biopsychosocial roots” of mental illness by helping consumers manage their medications to reduce impairments, connecting consumers to employment opportunities and providing psychosocial “training” to reduce “dysfunction and disability” in relationships, work and daily living (Anthony and Liberman 1986). Case managers supposedly helped consumers live a “normal” life in the community (Brodwin 2008; Hoge et al. 1994). The success of PSR programs and case managers was measured by the number of hospital days clients had in a given period, with more hospital days indicating less program efficacy (Floersch 2002; Lunbeck 1994).

Estroff et al. (1981, 1989, 1995, 2004) have illustrated the ways in which PSR services encouraged consumers to become “full-time crazy people” who subsist on meager government benefits, take advantage of social services, compliantly accept medications despite severe side effects, keep to themselves and obey their case managers (Estroff 1981). Consumers accentuated their “disabled” identity to establish “deservedness” for the government benefits they needed to subsist without competitive employment (Estroff 1989, 1993; Estroff et al. 1997). They then sought “continual treatment, management, and special response … to control or reduce suffering” even as those treatments “result[ed] in or creat[ed] additional dysfunction, signs and suffering” (Estroff 1993, p. 276).

To keep consumers living “independently” in the community, PSR case managers have practiced techniques of surveillance, control and intrusion (Brodwin 2008; Floersch 2002). Floersch (2002) detailed case managers’ micromanagement of consumers’ “medications, money, and manners.” A case manager might watch consumers swallow medications to ensure compliance, control how they spent their monthly disability checks to protect them from homelessness and hunger or stand outside the bathroom door while clients took a shower to encourage proper hygiene (Angell et al. 2006, 2007; Floersch 2002). To the average North American citizen, this seemingly Orwellian (1950) “Big Brother is watching” style of case management seemed invasive and paternalistic—far from the ideal of “normal” community-based living it was meant to produce.

Researchers and practitioners self-consciously identified these practices as “coercion” (Angell 2006; Angell and Mahoney 2007; Angell et al. 2006; Davis 2002). Brodwin (2008) depicted the moral tension in a case manager’s desire to promote consumer autonomy while taking care not to abandon them. Coercion was necessary, Brodwin (2008, p. 139) asserted, “to maintain contact with clients who do not meet their appointments, who sometimes disappear for days or weeks into a hospital or prison bureaucracy, or who simply want to escape the agency and its intrusions.” Within 1 year of withdrawing an assertive style of case management, one classic study found that consumers experienced a “higher frequency of decompensation” and hospitalization (Stein and Test 1985). After hospitalization, consumers were assigned to a case manager and started the process over again. Coercive practices, although possibly necessary, also had negative effects on the therapeutic alliance between case managers and their clients (Angell et al. 2007; Ragins 2003).

Caught in a cycle, many consumers eventually became costly “chronic” consumers who depended on case managers to make choices for them (Davidson et al. 2008; DeSisto et al. 1995; van Dongen 2004). “Chronic” consumers, in turn, developed a devalued sense of self and an inability to act in their own self-interest (Anthony 2000; Barham and Hayward 1998; Barrett 1998; Corin 1998; Desjarlais 1997; Estroff 1989; Grob 1994; Pettie and Triolo 1999; Ridgway et al. 2002; Wagner 2005). Mueser et al.’s (1998) meta-analysis of case management models suggested that PSR case management only minimally helped people with schizophrenia stay out of the psychiatric hospital.

Families of consumers (predominantly represented by the National Alliance for the Mentally Ill; NAMI), the Consumer/Survivor/Ex-patient Movement (C/S/Xers), clinicians, researchers and policymakers gradually banded together to form a “Recovery Movement” for mental health system reform. The Recovery Movement wanted a “culture of recovery” to replace the “culture of chronicity” (Anthony 2000; DHHS 1999, 2003; Fisher 1993; Fisher and Chamberlin 2004; Jacobson 2004; Spaniol et al. 2002). In 2003, the Recovery Movement garnered Bush Administration support. Hoping to reduce the cost of mental health care, the Bush administration issued federal mandates promoting “recovery-oriented services” (DHHS 2003; SAMHSA 2006).

A “recovery-oriented mental health system” (Anthony 2000) would promote consumer autonomy, empowerment and hope (Davidson 2003; Deegan 1996a, 2003; Dixon et al. 1994; Fisher 2005; Holter 2004; Jacobson 2001; Jacobson and Greenley 2001; Mead and Copeland 2000; Munetz and Frese 2001; Ridgway 2001; Solomon and Draine 1996; Spaniol et al. 1999, 2002; Young and Ensing 1999). Psychiatrist and C/S/Xer Dan Fisher (1993) described a “positive culture of healing” as “a culture of inclusion, caring, cooperation, dreaming, humility, empowerment, hope, humor, dignity, respect, trust, and love.” A “culture of healing,” Jacobson and Greenley (2001) observed, “begins with an environment characterized by tolerance, listening, empathy, compassion, respect, safety, trust, diversity, and cultural competence.” Table 1 specifies details of the proposed nationwide recovery-oriented changes.

“Empowered” consumers, recovery advocates hoped, would become more than “cases” to be “managed” (Chamberlin 1978; Holter 2004; McLean 1995; Mead and Copeland 2000; Sells et al. 2004; Townsend and Glasser 2003). A psychologist who has recovered from schizophrenia advised: “We are not subjects to be acted upon. We are fully human subjects who can act, and in acting, change our situation … we can become self-determining” (Deegan 1996a). Advocate Amy Jones elaborated:

> They say—that’s a great choice! Who do you say things like that to? Kids. I don’t care if you think it’s a great choice or not. Compliance stops critical thinking…. Sometimes we won’t make a good decision. Then we’ll learn … to weigh the costs and benefits so that we’re not afraid to deal with reality. The key isn’t to be rewarded. Why do we teach consumers that the only way to get what you want is to wait for someone to give it to you? (October 2006)

Acting autonomously, reformers hoped, would embolden consumers to become independent citizens rather than subjects of a “paternalistic” mental health care system (Aquila 2006; Fisher and Chamberlin 2004; Holter 2004). According to Jacobson and Greenley (2001), “Empowerment may be understood as a corrective

Table 1 Treatment principles of the "traditional" PSR model vs. the "recovery-oriented" model in the U.S. mental health care system

Principle	PSR model	Recovery model
Goals	*Rehabilitation*: stabilize illness, reduce negative impacts of illness; avoid rehospitalization	*Recovery*: community reintegration; a meaningful life for clients; minimize negative impacts of "traditional" mental health care
Assumptions	A person with psychiatric disability experiences "impairments, dysfunctions, disabilities, and disadvantages" that mental health services should reduce	Anyone can achieve recovery with hope, empowerment and peer support
Treatment locales	Psychiatric hospitals, nursing homes, community-based centers	The additional option of peer-run programs and drop-in centers
Treatment relationship	Case manager: educated, licensed professional directs client; physical, narrative and emotional boundaries limit reciprocity	Recovery support specialist or peer support specialist: experienced former mental health consumer as advisor; collaborative decision making that gives consumer final choice; reciprocity encouraged
Key treatment terminology	Compliant, stable, adherent, not rehospitalized	Freedom, empowerment, hope, autonomy, self-determination, social reintegration, anticoercion, self-advocacy
Medications	Prescribe and comply; involuntary or forced treatment when necessary; coercion is for client's own good	Educate and support; avoid involuntary treatment and coercion; use "advance directives"
Money management	Guardian/payee relationship	Help client learn financial independence
Personal choice	Paternalistic caretaking: Consumers may need help to make the right choices when they are "sick"	Self-determination: Consumers will best learn personal responsibility by making their own choices even if they try and fail
Employment	Some people cannot work due to their psychiatric disability and need to receive government disability benefits to survive	Everyone can work with the proper support; no one should be expected to live on meager disability benefits
Housing	Some people need to live in nursing homes and other protected environments	Everyone should be able to find affordable and safe housing in the least restrictive setting

for the lack of control, sense of helplessness, and dependency that many consumers develop after long-term interactions with the mental health system."

An Ethnographic Eye on the "Culture of Recovery"

Understanding efforts to change the culture of the U.S. mental health system required an ethnographic approach. A health care system is "both the result of and the condition for the way people react to sickness in local social and cultural settings, for how they perceive, label, explain and treat sickness … governed by cultural rules" (Kleinman 1980, p. 26). Any attempt to understand the way a health care system changes its institutional culture should build on accumulated anthropological knowledge about the relationship between culture and health care.

In many discourses, "culture," often defined as "a toolkit of beliefs, practices, notions, and things held dear" or "tools and strategies for meeting the essential tasks of life," has been used to explain 'unexplained variance' or serve as "a mock-elegant way of referring to 'there' as opposed to 'here'" (Hopper 2004, p. 65, 2008). Jenkins and Karno (1992) called this the "black box" of culture—a wastebasket category where factors like environmental degradation, overtaxed treatment resources and the effects of poverty or exotic beliefs all seem to go and then lose their meaning. This analysis of an attempted organizational change uses anthropologist Kleinman's (1999, p. 361) understanding of "culture" as "symbolic apparatuses of meaning making, representation, and transmission," which are "closely connected with political and economic processes and changes in relation to them" and are "realized in local worlds and yet extend beyond them." Culture is brought to individuals through "experience," or a "felt flow of interpersonal communications and engagements" that "take place in a local world" and are "thoroughly intersubjective" (p. 358).

Existing anthropological research provides valuable critiques of U.S. mental health care (Fossey et al. 2002; Hohmann 1999). Beyond Estroff's previously cited critique of PSR services, ethnographers have examined inpatient care on a psychiatric unit (Rhodes 1991, 1993), dual-diagnosis treatment (Alverson et al. 2000), the experience of homelessness and mental illness (Desjarlais 1994, 1997, 1999; Hopper 1988, 2003; Lovell 1997), why psychotic homeless women may refuse services (Luhrmann 2008), the use of case management models among psychiatric social workers (Brodwin 2008; Floersch 2002), the tensions between psychodynamically and biomedically oriented psychiatrists (Luhrmann 2001), clients' use of atypical antipsychotic medications (Jenkins et al. 2005), the continued experience of stigmatization after "recovery" (Jenkins and Carpenter-Song 2008) and establishment of "continuity of care" for consumers (Ware et al. 1999). Recently, schizophrenia researchers Jenkins and Carpenter-Song (2005, p. 380) have requested "studies that can empirically specify processes of illness exacerbation, improvement, and recovery." This article attempts to build on the existing anthropological literature while responding to this request.

Recovery at Horizons

For several decades, Horizons has provided PSR services to more than 6,000 consumers, or "members," through several PSR programs. From 2004 to 2006, I conducted fieldwork at one Recovery Center where about 80 members came each day to receive newly "recovery-oriented" PSR services. The Recovery Center housed two programs: Horizons' oldest PSR program, Riverside, which was attempting to become more recovery-oriented; and Horizons' newest program, run by former consumers, the Peer Empowerment Program (PEP). PEP was open Thursday through Sunday from 9 to 4 to accommodate homeless people who had nowhere to go on the weekends. Riverside operated Monday through Friday from 9 to 5.

The average Horizons' Recovery Center member was homeless and unemployed, received or needed help acquiring government benefits for people with psychiatric disabilities, had notably failed at managing his or her money and had sparse (if any) social support. Ninety-two percent of Horizons' members received government Social Security benefits, which gave them an income below the federal poverty level.[1] In the United States, unemployment rates for adults with schizophrenia ranged from 60 to 78% (Cook 2006, p. 1392; McAlpine and Warner 2001). Many wanted to work; half of adults with mental health disorders considered themselves able to work (Kaye 2001) and opinion surveys repeatedly found that most consumers desired employment services and supports (Cook 2006). Even so, finding jobs was difficult due to societal and self-stigma. Pescosolido et al. (2000) found that 64% of Americans did not want someone who had schizophrenia as a close coworker. The potential loss of medical insurance was also a major disincentive to work. People with mental illnesses in part-time and even full-time jobs lacked adequate mental health coverage (Cook 2006). In contrast, government psychiatric disability benefits guaranteed insurance coverage for expensive psychiatric services and prescriptions (Iglehart 1996). Subsisting below the poverty level (DHHS 2009) led many members to live a nomadic lifestyle on what Hopper et al. (1997) call the "institutional circuit." Members transitioned—hourly, daily, weekly, monthly—among institutions (e.g., hospitals, jails and prisons), inadequate community settings (e.g., shelters, YMCAs, nursing homes) and the streets (Hopper et al. 1997; Warner 2004). At least one-third of Usonians diagnosed with schizophrenia shared this fate (Warner 2004, p. 191).

For those subsisting on the "institutional circuit," recovery centers had great value. They provided a place to go during the day, a way to connect with case managers and peers, access to a hot lunch, some interesting training classes and sometimes even a family-style environment. While recovery centers were far from the ideal of "a job, a car, and a girlfriend" that most consumers ultimately desired, they were a good place to start.

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[1] There were two kinds of Social Security benefits available to members, based on their work history: Supplemental Security Income (SSI) and Social Security Disability Income (SSDI). If a member had a psychiatric disability and had *not* worked full-time for 10 years or more, he or she qualified for SSI. SSI offered a "wage" of $3.19 less per hour than minimum wage and stranded recipients below the national poverty level for 2009.

In 2002, Horizons' administrators decided to become more recovery-oriented by changing their use of the PSR model, noting that "it is not easy to let go of the … false (but comforting) certainties of traditional mental health—for example, that staff are the true experts (certainly not consumers!) on what "is best." A new Recovery Steering Committee rewrote the organizational "mission statement," to claim that Horizons' goal was "to make every Horizons program and department a center of excellence in providing recovery-based mental health services, where the messages of hope, choice, and wellness are consistently and kindly conveyed." In order for these changes to occur, Horizons' administrators announced, "Consumer choice, consumer empowerment, and consumer education about an array of life choices have become new fundamental principles."

Case managers were asked to let consumers manage their own lives through "empowerment" toward self-determination as suggested by federal recovery mandates (DHHS 2003, pp. 1–3). Empowering members, in some cases, meant allowing consumers to make "bad" decisions and fail in their endeavors, and thereby afford them the "dignity of risk" (Deegan 2003; Mead and Copeland 2000). As a "recovered" consumer explained at one national conference: "Sometimes growing and learning means taking risks and failing, like getting a speeding ticket. We learn from these experiences of failure and know what not to do again."

Despite these directives, members often endured the daily strain of poverty, crime, homelessness and stigma. Luhrmann (2007, pp. 158, 159) described these as experiences of "social defeat," or a "relentless pattern of demeaning encounters," "demeaning and disorganized services" and "little social support." As members of the "institutional circuit," subject to multiple experiences of social defeat, many of Horizons' members found it difficult to achieve empowerment.

Empowerment, Enlightened Self-Interest and North American Mental Health

Recovery advocates hoped that "empowered" consumers would act in their enlightened self-interest to "recover" a "meaningful life" as a valued self-made citizen who contributed to their community—the essence of North American mental well-being (PNFCMH 2003; Ridgway et al. 2002; WHO 2009). At the moral core of this "recovery philosophy" was the philosophical foundation of the U.S. social contract, according to which productive individuals are willing to make sacrifices in order to reap the benefits of mutual cooperation (Nussbaum 2006, pp. 16, 34). After traveling in the United States, de Tocqueville (2000 [1840], p. 610) described this style of reciprocity as *self-interest properly understood*: "American moralists do not claim one must sacrifice oneself for one's fellows because it is a fine thing to do but they are bold enough to say that such sacrifices are as necessary to the man who makes them as to those gaining from them." Founding father Benjamin Franklin claimed that citizens acting in their own self-interest would ultimately experience individual and societal well-being (Pangle 2007). "You may be more happy than Princes," Franklin (2005, p. 44) promised, "if you will be more virtuous."

Franklin thus promoted self-interested choices that reflected "American virtues" such as "industry," "thrift," "order" and "civility and honesty" (Pangle 2007,

p. 51). Such a citizen would be invited into the social contract, which granted them the "inalienable right" to "life, liberty and the pursuit of happiness (Jefferson 1776). De Tocqueville (2000 [1840], p. 612) observed these values in action, noting that "self-interest properly understood … does shape a host of law-abiding, sober, moderate, careful, and self-controlled citizens."

Describing people with "mental health" as valuable citizens who autonomously practice enlightened self-interest for the greater good continues to shape U.S. policies. Healthy People 2010 (NIH and SAMHSA 1999, 18-3), for example, defined mental health as "a state of successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and to cope with adversity … [which is] indispensable to personal well-being, family and interpersonal relationships, and contribution to community or society." In North America, acting autonomously for the mutual benefit of others proves one's mental health and validates one's moral worth (Buchannan 2008).

On the other hand, U.S. public health institutions refused autonomous choice and acted paternalistically toward people perceived as incapable of acting for the common good (Buchannan 2008). Usonians with schizophrenia were often viewed as just such people—"parasitic" moral and financial leeches who did not contribute to the greater good, regardless of the accuracy of those statements (Nussbaum 2006, p. 4). Recovery Movement advocates grasped what historians sometimes observed: "The core [North American] ethic … is one of personal responsibility for one's actions. To those who advocate this ethic, obeying entitles one to world success; violating it endangers the fabric of American society" (Jencks and Peterson 1991, p. 400). Some Recovery Movement advocates thus aimed to "empower" people with schizophrenia to make their own choices and demonstrate their ability to be responsible citizens capable of acting in their own enlightened self-interest with an eye toward the greater good. By doing so, they hoped that people with schizophrenia would be reinterpreted as valued citizens and invited to reintegrate into the relationships of reciprocity and interconnectedness that are the foundation of a "meaningful" North American life.

"Empowerment" at Horizons

Horizons adopted the Recovery Movement's suggestions to "empower" members and attempted to incorporate empowerment efforts into their organizational culture change. How were Horizon's attempts to empower consumers to recover experienced by staff and consumers? How did these attempts seem to help or hinder healing from schizophrenia? What lessons can we take from attempts to implement the recovery philosophy at Horizons to inform other similar efforts?

Staff Perspectives

Vera, a "recovered" consumer and Horizons' PEP director, strolled onstage with the ease of a comedian: "Okay, show of hands—How many people forgot their medications today?" As three out of several hundred people raised their hands, she cocked her head to the side: “Oh, you’re ‘lyin.’” Several people laughed. Vera shuffled across the stage, shoulders hunched:

> If you met me a couple of years ago, you would have seen me walking around overmedicated, no self-esteem, no self-worth and even more so—afraid. Afraid if I walked into a social service agency they wouldn’t help me with what I needed. I was afraid to make a move one way—to go back to work. I was afraid for another hospitalization…. My life was really changing for the worse until I became empowered. And then I realized that for my recovery it was more important than to help myself to help others. (October 2005)

She then expressed concern: “There’s some staff who … don’t want to give up the power and control. Staff need to change…. We need your help to change the behaviors and mentality of staff today! There are so many great ones and there are some who don’t get it.” The vast ballroom shrank as the members stood to join her as she chanted, “RECOVERY! GET IT, GET OVER IT, OR GET OUT!”

Vera later explained her definition of empowerment:

> Empowering yourself to take back your life means exercising your freedom of choice—a fundamental right you have as an independent individual person…. Do not see me and treat me as if I were disabled. That isn’t what I need from you … please see me as your neighbor, family and friend, not as a diagnosis!

To achieve empowerment, Vera advocated, members needed to “first be in control of their own money, meaning they have no payee.” They would also need to “have their own mind and make their own decisions … you don’t need to have anyone telling you what to do! Just do what you need to do.”

Bruce, a Horizons’ PSR case manager for 30 years, had other views on empowerment. His reputation for gently, persistently working with challenging “cases” preceded him. He thought that Horizons’ new recovery agenda accused him of “disempowering” or “harming” members. In turn, Bruce felt disempowered: “A lot of people [staff] wrestled with—Why are we doing recovery for members but treating staff like they’re expendable? The way recovery was rolled out as an agency initiative felt very paternalistic towards staff and staff picked up on that.”

Lola—a snappy dresser and case manager—also shared her sentiments:

> Case managers are at ground zero of all these ideas and rules and it’s not easy given what they have to work with. You want to empower people, but it only makes the members against us feeling worse. Recovery aggravated this and made it sound like staff was the enemy blocking the route to a better life. (April 2005)

One frigid day in February 2005, Shelby met a homeless member at a ramshackle McDonald’s in an industrial neighborhood. Meet Earl: bearded, lacking teeth, grizzled and gray, pensive and generally unresponsive, but grateful for the new boots Shelby offered. He immediately began unlacing his tattered tennis shoes with long, deeply cracked yellow fingernails, mumbling about frostbite. Shelby quietly suggested he change his shoes in the bathroom instead. “We don’t want to get kicked out, right, buddy?” she asked gently. As Earl walked toward the bathroom, Shelby sighed heavily. “I hope he doesn’t really have frostbite.” Her forehead creased with concentration as she spoke:

> So recovery says that my client has to make his own choices about meds and housing and what he does with his day and how he spends his money all by himself. I don’t make him follow any rules. And if my member chooses to drown—or even if he just can’t swim—then I let him drown…. Why? … I care about him. I don’t want to watch Earl drown; I am paid to help him. (February 2005)

Bruce also had reservations about the recovery philosophy letting members control their own money:

> I know full well he is going to use it all in those first few days to rent a hotel and smoke crack and get a prostitute … the rest of the month he will be broke, sick and tired and homeless and I will be almost powerless to help him with no money. Oh yeah, and I am not supposed to help because he has to take personal responsibility for his choices. And that’s recovery? Don’t you think if poor life circumstances were going to inspire him to change they all ready would have? (May 2005)

As he spoke, he shared the wizened look of his clients. Case managers often shared the fears, sorrows, frustrations and small victories of the members. Some took up their clients’ yokes when their clients set them down. Many fought for people’s survival when people didn’t care to survive. They navigated the labyrinthine and cruel institutional circuit daily. They carried the burden of guilt and professional shame when a consumer was rehospitalized and accepted the agony of having clients who committed suicide or died prematurely or disappeared. Every single day they were expected to be reasonable, compassionate, supportive and hopeful, and now “recovery” said they also needed to let consumers make potentially ridiculous choices in the name of empowerment.

“I don’t want you to be disappointed,” Bruce sighed, “if it [recovery at Horizons] doesn’t work out.” He stroked the gray stubble on his chin. “We might fail—just like the members. Is that okay, if staff fail, too? You might really burn out staff this time … take the occasional reward of 6 months of stability for our members away from us. Then what are we there for?”

Other case managers agreed with Bruce. “Members don’t know how to do recovery, and they’re used to having their hand held,” Max told me with an indignant expression. “Right!” interrupted Bill with a growl. “Members are used to us being more paternalistic and now they think we’re hanging them out to dry, I mean, they were not at the trainings. They think recovery is some substance abuse thing. We need more time and staff to teach them what’s going on.”

Laura nodded in agreement, her blue eyes bright with urgency: “It’s scary for some members—for the past 20 years we have fostered dependence and now it’s scary for them to do it by themselves.” Veronica also expressed genuine concern: “I see more hospitalizations with my clients…. Some members can’t handle the stress of change and choice.”

Even though recovery advocates thought that consumer failures were actually a necessary and natural part of empowerment, signs of failure made case managers uneasy. Many felt "empowering" treatment processes encouraged them to abandon "their" members. "Right now," Mabel added, "[recovery] seems like a yellow brick road leading in every direction! Some people would sit in a chair all day and call it recovery if they weren't told what to do! Recovery isn't sleeping all day! Firmness and direction are a necessity!… They wouldn't be here if they didn't need us."

Other staff felt that recovery was adding an invaluable dimension to the dialogue between staff and members. Twenty-something Moe scoured the streets to recruit homeless mentally ill people by day and played the mandolin in a country band at night. He shared his view:

> It's not so much that staff *know* better. We learned from experience…. Like going away to college … a lot can manage more than we think. We all do it everyday and live with the consequences. Case managers just have to figure out where the gap is for the member between what is okay—what the person is able to do—and what they aren't. (February 2005)

Overall, the professional staff I interviewed appreciated the *ideas* behind empowerment. Like Vera, they *wanted* members to be empowered and recover, but unlike Vera, they were concerned that the practical details had not been adequately addressed. How would recovery-oriented services work? How might recovery affect their job security? Would they be held accountable for member failures and relapses under an empowerment model as they were currently held accountable for member rehospitalizations? Did they have enough hours in the day to deal with explaining recovery, having members trying and failing, then doing all the billing paperwork required when they each had a caseload of 13 members? Even so, many appreciated the energy the idea of empowerment brought to the organization. The Riverside Program Director, Jacob, settled into a leather seat in his office with a steaming cup of tea and explained, "We're not asking—What am I going to do? But how can I help you do what you need to do? We are encouraging people to be more independent—that's a good thing."

Horizons' case managers were caught in a Catch-22. How could they empower members to try and fail and still protect them from harm? To do so, case managers felt they walked a thin—often-arbitrary—line between neglect and empowerment.

Members' Perspectives

To be empowered, members first had to learn what recovery and empowerment actually meant. At one Recovery Steering Committee meeting, members tried to pin down the meaning of "recovery" in preparation for Horizons' annual lobbying trip to the capitol. Ralph—a bespectacled, flannel-wearing member in his 40s—asked the peer leaders in charge of the rally—Melanie (Horizons' Peer Director), Aaron (a former attorney and consumer activist on Horizons' Board of Trustees) and Carolyn (a peer working for the state Department of Mental Health)—to explain "what recovery meant." The following dialogue ensued:

Aaron: Nothing about us without us. We decide what getting better means and what it is

Ralph: That makes sense, but I am looking at the big picture. There are lots of people in the mental health system who are unable to decide. How do we put a system in place to meet the needs of individuals?

Carolyn: We aren’t capable of coming up with solutions. The point of the rally is to educate legislators about recovery so they know what’s possible and to ask legislators to take appropriate action

Aaron: This is a big process. We can’t just tell you in a half-hour

Ralph: Last year I had the ear of my senator and I didn’t know what I was talking about. I was embarrassed

Aaron: We’ll do it better this year. Thanks for reminding us

Ralph: Well, as soon as I figure out what recovery is, I will feel better

Aaron: [Winking at Ralph] I will, too. (March 2006)

On rally day, Horizons’ staff doled out hundreds of “action folders” to members along for the ride. Members streamed into the capitol, wearing blue plastic “Recovery Rocks” rain ponchos (despite the sunny day) and toting Xeroxed letters to sign and personally deliver to their representatives. As Ralph walked into one representative’s office, a startled secretary quickly eyeballed him, leapt from behind her desk, grabbed his entire folder, thanked him and herded him out the door. The whole process took 1 min. On the bus ride home from the rally, Ralph reflected: “I didn’t actually see my senator this year so it wasn’t as big of a deal but I still felt like people were telling me what to say without telling me what it meant. I still want to know more about recovery.”

Horizons’ Recovery Steering Committee tried to disseminate more information about recovery to members. They hosted a one-day “recovery” conference that about 500 of 6,000 members attended. They printed 4,000 laminated wallet-sized recovery reference cards. One side described “the worker’s role in recovery,” which included the following: “Communicate a belief that a person can and will recover”; “Do not judge, dismiss or advise”; “Engage in conversations about goals, dreams and wishes”; “Ask questions”; “Share success stories” and “Believe in the potential of each person to recover in their own way.” When asked, staff seemed to understand what this meant. On the “member” side was an answer to the question, “What is recovery?” The answers to the question included: “Changing attitudes, values, feelings, goals, skills, and/or roles”; “Overcoming internalized stigma”; “Reclaiming a positive sense of self”; “An ongoing personalized journey of healing and transformation”; “Reclaiming and strengthening roles beyond being a consumer in the mental health system” and “Actively self-managing one’s life and wellness.” A few members complained that the jargon was confusing. No one could say how many members and staff actually received the cards either.

Networking limitations also constrained grassroots self-advocacy. Members did not have voicemail, phone calls were costly (35 cents each) and messages left at front desks had to be brief. Widespread program bulletin boards were underutilized and typically ignored. Many Horizons programs lacked Internet access, which ruled out e-mail and Web sites. Program representatives attended monthly Members’

Advisory Council meetings to report what they learned back to members at their programs, but usually 10 or fewer of 100 programs were represented.

Even when they did know they were supposed to be practicing "empowered" self-advocacy, members feared reprisals. This exchange between Barb (a high-ranking administrator) and two member representatives, Ella and Lynn, reflected these concerns:

> *Member Ella*: Members are afraid to speak up. You get labeled a troublemaker. You follow your little handbook guidelines and you get ignored. And then … I hear that all the time—well, if you don't like it, then you can live somewhere else. That's not empowering. It's the opposite.
>
> *Member Lynn* (who also works full-time in the Education Department): I … hear people get threatened with housing all the time.
>
> *Administrator Barb*: Well there are pockets of poison in the organization—people who just don't get recovery. We need to get rid of those staff and we will, but it's going to take time.
>
> *Member Ella*: That doesn't make me feel any better about my housing, honestly. Until Horizons can guarantee that members speaking up for themselves won't just be seen as just talking back, a lot of people are going to stay quiet. (July 2005)

"Staying quiet" rather than "talking back" made sense to members who aimed to cultivate tranquility and stability in their lives.

Members also preferred to use staff assistance and were perplexed and annoyed that one of their favorite survival strategies now meant that they were "unhealthy" or "disempowered." Barnie, President of the Members' Advisory Council, battled his unruly glasses as he explained:

> I suck at money. And I've been told that this is a problem with recovery. A hindrance. I have bad credit and no checking account and so I have a rent payee. Part of my recovery is realizing that I have a problem with money and need a rent payee. People need to stop telling me this is a problem, people! (9/2006)
>
> Dolores rolled her eyes in agreement and fluffed her curly brown hair:
>
> Everyone acts like it's so bad that I still come here. I have had my own place for 20 years. I do volunteer work on a psychiatric ward helping other people think about recovery. I am very happy! But I still come here … twice a week for company—Is that so bad? (March 2006)

Gary also had an apartment, a roommate and a part-time job washing dishes. He had not been hospitalized for 10 years.

> I feel connected here. The pretty lady case managers smile at me here and ask me how I am doing. If that makes me not recovered, then fine! If recovery is my choice, then I can choose to not recover because if I leave here I would be

> lonely with no women's smiles and then I wouldn't maybe be able to go to work and relapse. (February 2006)

Staff and members at Horizons struggled to implement Horizons' recovery philosophy. While staff that were "recovered" former consumers wholeheartedly endorsed the recovery philosophy's idea of empowerment, professional staff worried about the details of putting the philosophy into practice. "Would the potential stress generated by recovery-oriented practices complicate and potentially worsen members' short- and long-term outcomes? Can members with schizophrenia really handle making their own choices?" they wondered. Members were also reluctant to embrace Horizons' recovery philosophy. With neither a working understanding of what recovery meant nor the power or resources to effect organizational change, members had trouble justifying a shift in subsistence strategies. Even though the recovery philosophy promoted the constructive qualities of stress, members feared that increased stress would lead to a psychotic episode and require hospitalization. After such a relapse, members typically had to deal with homelessness, unemployment and a host of financial and interpersonal repercussions. Many times, members felt that they knew this from years of experience. "Wouldn't it be *dis*empowering," they wondered, "to take a relapse prevention strategy away from them?"

Conclusions

Many Horizons' members enjoyed the caretaking and sense of belonging they experienced as members. At Horizons, they could build a valuable community identity in a safe, somewhat permanent environment with sympathetic others. In that context, members could build the relationships of reciprocity in a family-style setting that were otherwise generally unavailable to them. Horizons, recovery initiatives suggested they should do more to establish their value, which implied that what they were doing was not valued and opened up the possibility that long-term "members" would come to be understood as people who had failed to become valued citizens.

Rather than creatively considering alternative ways in which members might find hope and fulfillment, Horizons' recovery initiatives relied on typical North American notions of ideal citizenship. Institutional barriers—a lack of communication capabilities, fuzzy and confusing definitions of recovery developed almost exclusively by staff, no real sense of what was supposed to change or if it could be changed and a continued ability for staff to trump any member initiative—also impeded the kind of "recovery" proposed by the Recovery Movement. The local strategy for maintaining mental health, "staying quiet," remained the dominant way in which members managed stress. While many members openly longed for the "more meaningful" life that Horizons' recovery philosophy urged them to acquire (as one member explained, "a girlfriend, a car and a job"), most opted to maintain a caretaking relationship with Horizons. Empowerment, many concluded, was too stressful and not worth the risk of relapse. A cultural mismatch occurred, then, between the immediate needs of Horizons members with schizophrenia—supportive ways to *reduce stress*—and Horizons' focus on the typical expectations of valued U.S. citizenship—the ability to act in one's own enlightened self-interest—which seemed to *generate stress*.

Reforms that generate stress could lead to negative outcomes for people with schizophrenia, who have difficulty coping with even typical amounts of stress (Corcoran et al. 2003; Yung et al. 2003). The "diathesis-stress model" of schizophrenia (Millon et al. 1999; Norquist and Narrow 2000; Walker and Diforio 1997) claims that a "genetic predisposition" increases people's "constitutional vulnerability" to everyday stress (Corcoran et al. 2003; Halsband 2002; Jones and Fernyhough 2007; Nuechterlein et al. 1992; Phillips et al. 2006; Walker et al. 2008). For such people, environmental stressors may trigger an overactive "stress response" (e.g., HPA axis), causing a "stress cascade" of neural events that lead to psychosis (Corcoran et al. 2003; Walker 2009; Walker and Diforio 1997; Walker et al. 2008). Life course events such as prenatal factors (e.g., maternal influenza in the second trimester [Limosin et al. 2003]) and childhood trauma may increase stress vulnerability (Read et al. 2001). In addition, the chronic stress associated with political and economic disenfranchisement increases the incidence of schizophrenia and worsens the prognoses for recovery (Adler and Newman 2002; Baum et al. 1999; Bhugra 2004; Boydell et al. 2001; Harrison et al. 1997; Kelly 2005; van Os 2004; Williams et al. 1997).

On the other hand, the "culture" that helps people manage their stress may promote better prognoses. The same psychophysiological pathways by which stress is internalized (Taylor et al. 2010) may also be used to promote resilience to stress. People "in recovery" in the U.S. use stress-reduction techniques like yoga and meditation to improve their mental health (Copeland 2008; Deegan 2002; Ridgway et al. 2002). Recent clinical studies using these techniques for people with schizophrenia have had positive results (Chadwick et al. 2009; Duraiswamy et al. 2007; Jha 2008; Shannahoff-Khalsa 2004; Taylor et al. 2009). While we must consider the vulnerability of people with schizophrenia when offering them new therapies, these techniques appear to be effective for some. Qualitative research might tease out some of the reasons why these interventions help some people heal.

Indeed, culturally meaningful stress management techniques may explain improved schizophrenia outcomes in the "developing" world. Following up on work by Cooper and Sartorius (1977), Bresnahan et al. (2003, pp. 29–30) proposed that increased family involvement, informal economies, less segregation of the mentally ill and community cohesion all contributed to improved prognoses in developing countries. These favorable sociocultural factors may be understood as contextually relevant practices and processes that reduce stress or increase resilience.

In developing India, families supported patients by staying highly involved in the ill person's care, including accompanying them during hospital stays (Nunley 1998; Skultans 1987). Families also showed low levels of "expressed emotion" (consistently negative family attitudes), which is correlated with lower rates of rehospitalization (Corin 1990; Jenkins and Karno 1992; Leff et al. 1987a, b; Wig et al. 1987a, b). Indians diagnosed with schizophrenia maintained meaningful roles in family life (Hopper 2004). Due to the importance of *dharma*, children and the continuity of lineage (the children of mentally ill people were considered no less important), Indian parents made great efforts to secure a marriage partner for their mentally ill child, knowing that marriage would protect them from stigma, especially if they had children (Thara et al. 2003). Overall, people with schizophrenia in developing countries were more likely to be married than those in developed countries: 71% of males and 74% of females versus 28% of males and 48% of females, respectively (Hopper 2004). Staying connected to family and maintaining valued family roles may be one potentially effective, culture-specific strategy for stress reduction.

Less stressful work roles and expectations may also promote better outcomes in developing countries. In the US, "useful work may slow or arrest the evolution of disability" (Hopper and Wanderling 2000, p. 841), as meaningful social roles are acquired through work performance in a competitive market (Bellah et al. 1996; Warner 2004). However, many North American entry-level jobs are in stressful settlings like McDonald's: fast-paced, high-demand environments with intensive interpersonal interaction (Warner 1994). In India, less stressful migrant-labor markets enabled smoother entry and adjustment between periods of illness (Warner 2004, p. 171).

Workers in developing countries also faced different expectations of professional achievement (Halliburton 2004). In India, families did not expect people with schizophrenia to be a primary breadwinner, become financially independent or be consistently useful to the household (Padmavathi et al. 1987). People with limited competencies could access socially valued nonmarket roles regardless of productivity (Hopper and Wanderling 2000, p. 841). Skultans (1987), for example, described how mentally ill women with nowhere else to go could practice trance at a temple to increase their social standing.

Another sociocultural feature that contributes to better outcomes in the developing world seems to be less segregation of the mentally ill. In the United States, there is a long tradition of segregating the mentally ill that began when Franklin (1754) successfully petitioned for the first public hospital for "lunaticks … a Terror to their Neighbours, who [were] daily apprehensive of the Violences they may commit." North Americans still fear the mentally ill. In 2003, 61% of Usonians thought people with schizophrenia were dangerous to others (PNFCMH 2003). In another study, 38% of Usonians said they were unwilling to be friends with someone having mental health difficulties (Pescosolido et al. 2000). Despite these fears, Usonians with schizophrenia who did not abuse drugs were no more likely than people in the general population to commit a violent crime (Monahan et al. 2001).

Contrast the North American exclusion of people with schizophrenia to alternative examples from developing Africa. Burkina Faso's Dagara tribe believed that community efforts to help a mentally ill person "result[ed] in a release [of] that person's gifts to the community—the very gifts won through the person's intense dealings with the Spirit" (Somé 1999, p. 97). The author added: "Every time I encounter a modern person … whom other people refer to as crazy, I wonder what gifts are being lost to the community." Anders (2003) also described an African community where mentally ill individuals received formalized outreach, mentoring and a guided community-based meaning-making process to strengthen their sense of purpose and identity. Anthropologist Victor Turner (2006) described this as *communitas*, an experience of interconnectedness and homogeneity created between people in healing rituals. Cultural sponsorship of healing practices and a commonly held belief in the ill person's potential for cure can be more important than the specific practices or beliefs of the healer or patient (Levi-Strauss 1972, p. 180; Turner 2006; Warner 2004). The inclusion of people with schizophrenia in their local communities in contextually meaningful ways may also reduce stress, promote *communitas* and contribute to better outcomes in the developing world.

What lessons can be learned from this research?

Stress management is essential to helping people with schizophrenia in various contexts and should be central to plans for promoting healing. As the World Health Organization (Lancet Global Mental Health Group 2007) exports the PSR model to developing countries, we must trumpet its well-documented potential to produce stress.

We must also critically consider the implementation of recent "recovery-oriented" services that allegedly change the culture of the PSR model. The Recovery Movement's philosophy may serve as a corrective to the negative effects of the PSR model, depending on the ways in which it is implemented and in what context. The broader recovery philosophy promotes self-determination and invites us to value the perspectives and projects of people in context. When distanced from North American expectations of valued citizenship, the original recovery philosophy is open to grassroots, marginal, singular interpretations of how individuals find ways to cope with distressing psychiatric symptoms and find a place in the world. I encourage such distance, lest the broader recovery philosophy be haplessly discarded as ineffective based on poorly planned and executed culture-specific implementations like the one I have described at Horizons. Recovery-oriented services are probably best developed from the ground up by the people who use them.

Helping people with schizophrenia cope with and reduce the stress in their daily lives in personally relevant and culturally available ways may be a key aspect of any recovery-oriented treatment. Some of these understandings and practices may be highly specified for local needs, but they need to be preserved. Ethnographers should take stock of such strategies, by eliciting, documenting and preserving local stress-reducing practices and local definitions of meaningful citizenship so they can be incorporated into any on-the-ground plan to promote healing from severe mental illness.

If decades of ethnographic research on the PSR model are not used to inform the exportation of the PSR model to developing countries, an opportunity to close the "gap" in available global mental health services in ways that promote healing from schizophrenia may be lost. While there may be a need for more services for people diagnosed with schizophrenia in the developing world, we must ensure that those interventions occur in stress-reducing, locally meaningful ways. We must not impose North American ideas of valued citizenship on those we seek to help, especially when achievement of this ideal has proven to be so stressful for North Americans with schizophrenia. If these lessons are not heeded, the better schizophrenia outcomes we have seen in developing countries for decades may decline in the push for one global fix-all for mental health.

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