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Finding A Place in the World: The Experience of Recovery from Severe Mental Illness

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ARTICLE

Finding A Place in the World

The Experience of Recovery from Severe Mental Illness

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ABSTRACT

This hermeneutic phenomenological study of 45 adults with serious and persistent mental illness (SPMI) examines the experience of recovery over 3 years. After a brief review of the results from the first two phases, this article reports the findings from the third phase of the recovery process. Five essential themes are identified: (1) reintegration in the community; (2) reintegration with family and friends; (3) reintegration with the case manager; (4) reintegration with oneself; (5) barriers to social inclusion. Findings highlight the unmet needs for consumers in their relationships with case managers and barriers to inclusion at the macro level. Implications for practice include the delineation of client and case manager tasks specific to each essential theme.

KEY WORDS:

hermeneutic phenomenology

lived experience

mental illness

recovery

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The formative policy of the United States Joint Commission on Mental Illness (Appel and Bartemeier, 1961: 4) focused on deinstitutionalization and the development of community treatment: 'The objective of modern treatment of persons with major mental illness is to enable the patient to maintain himself in the community in a normal manner'. Although the policy was well intentioned, there have been multiple unintended consequences of the deinstitutionalization movement: revolving door rehospitalizations, homelessness and victimization of persons with mental illness (Davidson et al., 1998; Torrey 1988).

Prominent in the list of unintended consequences is social isolation. First person accounts and qualitative studies poignantly highlight the experience of loss, loneliness, and the desire for meaningful human connection (Bradshaw et al., 2006; Davidson and Strayner, 1997; Davidson et al., 1998;). Yet these individuals have fewer social contacts (6–12) compared to the general population (31–40) and their relationships are characterized as one-dimensional in that they receive more than they give (Cohen and Sokolvisky, 1977; Wallace, 1984). Other studies have reported that 50 percent of persons with schizophrenia have no friends or important relationships (Breier at al., 1991). Many individuals have conflicted relationships with family members and may no longer have contact with these individuals. For others, family is the primary support but the burden experienced by family members is overwhelming (Marsh and Johnson, 1997).

Social isolation is frequently considered to be an outcome of psychiatric disorders and related factors including severe symptomology, neurobiological deficits, impaired information processing, poor judgment and social skills deficits. Besides those factors specific to the disorder, Davidson et al. (2001a) highlight that social context, processes, and barriers are major contributors to social isolation and impede integration into communities.

For example, a primary contributor to social isolation is social stigma associated with having severe mental illness. Corrigan (2002: 223) has described social stigma as 'the social embodiment of disempowerment'. Stigma furthers social isolation because it promotes inaccurate portrayals of people struggling with mental illness. Results of two studies of over 2000 people in the USA and England reported three common themes that described public attitudes toward persons with mental disorders: (1) fear that mentally ill persons are dangerous and should be excluded; (2) authoritarianism based on the perception that persons with mental illness can't make their own decisions; and, (3) benevolence based on the idea that people with psychiatric disabilities are like children and should be cared for (Brockington et al., 1993; Taylor, 1980).

The pervasiveness of social stigma creates loss of opportunities for persons with mental illness. They are less likely to be hired or approved to lease an apartment. They are more likely to be falsely accused of violent crimes (Corrigan, 2002). The effects of self-stigma are corrosive as well. Studies show that persons with mental illness have reduced self-esteem, demoralization and

engulfment in a mentally ill identity (Bradshaw and Brekke, 1999; Corrigan, 1998; Lally, 1989; Link, 1987).

The intersection of mental illness, social stigma, discrimination and poverty also create powerful barriers to social inclusion: limited income from benefit programs reduce opportunities to participate more fully in society. Restricted housing opportunities geographically segregate persons with mental illness. Entitlement programs such as Social Security create disincentives for work. For example, high percentages of people with psychiatric disabilities can work yet few are employed and most work part time at minimum wage (O'Day and Killen, 2002). The threat of potentially losing social security benefits and medical coverage create significant barriers to pursing employment.

In contrast to these barriers, some studies have delineated elements that increase social inclusion for persons with psychiatric disabilities. Using basic needs as the foundation for social inclusion, housing, employment, education and a sense of belonging are considered essential. Similarly, the presence of one or more supportive people who provide hope, encouragement and opportunities is critical for social inclusion (Spaniol et al., 2002). Research on supported socialization, in which community volunteers are paired with persons with disabilities, has found increased social inclusion for persons living with severe mental illness (Davidson et al., 2001a; Skirboll, 1994). Davidson et al. (2001b) have identified three dimensions of social inclusion. These include (1) experiences of friendship, (2) feeling worthwhile through meaningful activity, and (3) hopefulness.

Several studies have explored methods for changing stigmatizing and discriminatory behavior in the general public. Educational approaches have shown significant changes in attitude toward mental illness but not in behavior. Direct contact with a person with psychiatric disabilities has shown significant change in attitude and increased helpful behaviors toward persons with psychiatric disabilities compared to education (Corrigan et al., 2001; Holmes et al., 1999).

This study reports the results from the third year of a three-year longitudinal study of the lived experience of persons with mental illness who are participating in community case management services. The case managers who provided services to clients were professional social workers at either the BWS or MSW level. The case managers' work with clients was grounded in a person-environment perspective that provided a model for their assessment and intervention in various environments. The common tasks for a case manager include crisis intervention, connecting people to resources, supportive therapy, development of educational or occupational goals and medication monitoring. As mediators between systems, they perform a host of tasks related to the recovery process.

This research identified three broad phases of recovery. The boundaries between phases were not precise and there was movement between phases. The

first year was characterized by demoralization, the experience of being over-whelmed by disability and the attempt to get some degree of control over the illness. The second year was defined by the development of mastery and coping with the consequences of illness. The third year was characterized by the theme of reintegration into community. See Table 1 for an overview of the recovery phases and related themes and tasks.

The specific aims of the current study are to (1) understand the develop-mental process of recovery over time, and (2) understand the significant inter-actions between person, illness, case manager, family and community that facilitate or hinder the process of social inclusion in the community.

METHODS

Subjects

Subjects were recruited from a non-profit mental health provider of services to persons with severe and persistent mental illness in a north central state. Services included assertive community treatment teams and less intensive case manage-ment services. A total of 60 subjects were consecutively referred to the study over the four-month period after their entry into mental health agency. Inclusion criteria for the study were (1) a diagnosis of schizophrenia, schizoaffective, bipolar, chronic major depression and substance abuse; (2) agency involvement for no more that four months, and (3) no evidence of a primary substance dependence diagnosis or organic brain syndrome. Five clients were excluded because of a primary diagnosis of substance dependence; five clients declined participation in the study; six clients were deemed too severely ill to partici-pate in the study. Informed consent was obtained from the 44 subjects who participated in the study. The average age of subjects in the sample was 37 (SD = 10.57). The average length of illness was 18 years (SD = 10.50). Of the total sample, 68 percent were female and 32 percent were male. Seventy-five percent of the subjects were Caucasian and 25 percent were persons of color. Moreover, 53 percent had a diagnosis of schizophrenia or other psychotic related disorders, 40 percent had a mood disorder diagnosis, and 7 percent had other diagnoses.

Research Method

A hermeneutic phenomenological paradigm guided the research approach. Hermeneutic phenomenology attempts to find, describe, and understand the individual's subjective experience by systematically determining the common and unchanging components, or 'essences' of a particular phenomenon, e.g. being a person with severe and persistent mental illness (Davidson and Stayner, 1997; Giorgi, 1985; Giorgi, 1997; Van Manen, 1990). Essence stands for those characteristics without which an object would not be what it is. To determine the essence of the phenomenon (or object), the researcher employs the process

Table 1 PHASES AND TASKS OF RECOVERY

Phase I – (0–1 year)	Phase II – (1 year–2 years)	Phase III – (2 years–3 years)
Demoralization	*Developing & Establishing Independence*	*Efforts Toward Community Reintegration*
Striving for Independence • Overwhelmed by disability. • Wish for normalcy. • Struggle with dependency. **Pacing Recovery** • Contemplating change. • Pacing recovery: Balancing stimulation. • Return to previous interests/hobbies.	**Developing Mastery** • Struggling with disability. • Taking back control of one's life. • Initial experiences of mastery.	**Reintegration of Self & Illness** • Making meaning of illness. • Cope with shame, internal stigma, grief.
"Life is happening around me" • Loss of hope – demoralization. • Everything is too fast, complicated. • Can't keep up. **Wish for meaningful community participation** • Immersed in mental health systems. • Loss of relationships & positions. • Stigma of mental illness.	**Coping with Consequences of Illness** • Coping with or solving life disruptions resulting from illness. • Beginning efforts to reconnect. • Dealing with societal stigma & discrimination.	**Reintegration in Community** • Reintegration in community. • Reintegration with family and friends. • Making meaning of illness. • Cope with external stigma & lack of opportunities.
Case manager "In there with me" • Dependent Alliance. • "Help is here". • Feels known as a person. • "Worker is on my side". • Worker provides supplemental functioning.	**Evaluation of Case Manager Relationship: Conflict and Impasse** • Client provides own supplemental functioning. • Conflicted alliance. • Case manager re: goals, difference with power & control. • Break with case manager.	**Reintegration with Case Manager** • Positive collaborative alliance. • Termination – loss of relationship.

of free imaginative variation. This process entails the varying of examples and elimination of those elements that are not considered essential to the existence of a particular phenomenon. What remains is the essence. Giorgi (1988: 172) gives the following example: '. . . I can imagine changing the materiality of a chair from a plastic to wood and still have the chair, but I cannot remove the seat and still make the same claim'.

Although hermeneutic phenomenological research seeks the essence of the experience, there is the realization that the interpretation of that experience is socially constructed by the participants themselves and also co-constructed with the researcher. 'Truth' therefore is always inherently tentative and relative to the context of the research.

Data were collected through semi-structured interviews that were tape-recorded. Interviews lasted from one to two hours and focused on five questions: What are your life aspirations? How does participation in MHR services help you achieve your goals? What do you do that helps you achieve your goals? What obstacles do you experience in recovery? What do you need that you don't have that would help you in recovery?

In the data analysis, codes were first assigned and then clustered based on a holistic and line-by-line reading of all transcripts as well as across-case comparisons. Codes were grouped to develop second order constructs that were then organized into clusters, which were given names as provisional themes. Essential themes were determined using the process of imaginative variation (Giorgi, 1985, 1997). Imaginative variation is a process whereby the researcher takes concrete examples of a thing or phenomenon, and imaginatively subtracts one feature, then another, from the examples to determine the core or essence of the phenomenon across cases, discovering in the process which features are essential and which are not. In the data from Time 1 of this study, for example, a provisional theme labeled 'searching for spirituality' was considered as a possible essence of subjects' experience. When this theme was checked against the data in the transcripts for validation, 'searching for spirituality' was not uniformly present in all subjects' lived experience. Consequently, it did not meet the criteria for consideration as an invariant component of what it is like to be a person in recovery from severe and persistent mental illness. Subtracting this provisional theme, however, illuminated a variant that was essential to the phenomenon that was labeled 'in there with me' and referred to the quality of the relationship with the case manager during Time 1. Not only was this essential theme found in the recovery experience for all subjects, it embodied the sense of belief and accompaniment that had been ascertained when the provisional theme labeled 'searching for spirituality' was under consideration.

Once the essential themes were determined, each transcript was recoded using the computer software *Atlas-ti*. This procedure let the researchers go through the transcripts again in order to pull out the relevant quotes to support each theme.

Because qualitative research uses the researcher as the instrument of data collection and the center of the analytic process (Patton, 1990), it is necessary to establish mechanisms that hold the researcher accountable for the disciplined use of her/his subjectivity. One method is for the researcher to be internally reflexive and forthcoming about her or his process (Armour, 2002). In addition to keeping an audit trail of raw data as well as a log of experiences, emotions, insights, and questions by the interviewer (DR), two consultants were used to monitor the influence of subjectivity on the data. The first consultant (WB) 'shadowed' and challenged the research process by independently listening to the audio taped interviews, writing reflections on the interviews, substantiating the determination of the essential themes, and reviewing the findings against the associated quotes from the transcripts. The second consultant (MA) was a specialist in hermeneutic phenomenological research. She reviewed method-ological procedures, the essential themes, and descriptions of the themes.

RESULTS

Although the second phase of the recovery process is characterized by the dialectic between mastery, the loss of mastery and efforts to regain a sense of control over oneself, the third phase is characterized by increased awareness of the disruption illness has had on one's life, continued improvement, and the development of mastery in the broader social arena. Consumers are managing their disability and attempting to return to important social roles, 'to find a place in the community'. There are five essential themes that comprise the third phase in this study of the recovery process: (1) reintegration in one's communities, (2) reintegration with family and friends, (3) reintegration with the case manager, (4) integration of self and illness, and (5) barriers to social inclusion.

Reintegration into the Community

Social reintegration in one's community emerged as the organizing theme in this study. As respondents gained more control in managing their disability, they attempted to resume important life roles in education and work and with friends and family. They report sentiments such as: ' I wanna get out and do some-thing'. 'It doesn't necessarily help me when I have five or six days off between work'. 'I want more people in my life'. One woman expressed her desire for greater involvement by saying, 'I thrive off of being in the community. I love it!'. Another man said, 'You can only learn so much in a hospital. You need to be out in society where you have to deal with problems . . . if you never deal with them, how do you know you can handle them?'.

Most respondents, however, indicated that reintegration is a struggle. They reported an awareness of a 'disjuncture' or a split between where they used to be socially positioned and where they are now. This disjuncture was particu-larly evident in their adult roles. Many have been out of work. One man told

how 'I used to take my resumé into a job. They smile, say "when can you start?" . . . [now] I go to these piddly places like Home Video and like Wendy's. [I] bring out my resumé and like they won't hire me. And I'm not used to that'. Another man said 'I would love to get a job in the computer operations field again, but it just seems that it's not out there right now . . . I've got a very bad work record since '96, so it's sort of hard to sustain, to get into something'. A woman described going back to a job she had previously held and how surprised she was by the current employer's response. 'They didn't know who I was because I'd never worked with those people before . . . I was like a blank sheet of paper to them'. People spoke of difficulties being out of work, returning to a former workplace after significant turn over, and encountering stigma, i.e. being treated differently once they returned.

Respondents sought connections in the communities where they lived. One man sought relationships with other tenants in his apartment building, saying 'that'd be nice to live in a building where everybody knows each other; I'd like that'. Relationships, however, were not easily found. For example, a woman described her frustration when she discovered the truth about who else lived in her building. 'I keep getting these weird complaints, and finally I asked the lady [casemanager]. I said, "Who are my neighbors?" "Oh, I forgot to tell you when you moved in, everyone that lives here is a senior citizen." I am 18. This is my first apartment, and you put me with a bunch of senior citizens? Oh, good'.

Respondents described not knowing how to re-establish ties in communities where they had lived previously. 'There was a church I was going to. Maybe I should go back there'. Some respondents attempted to maintain what they had before their illness. 'I'm also trying to carry on some of the friendships that I've had'. Yet many described these efforts as difficult, saying it's hard to know where and how to meet people 'cause you just don't, you just don't meet people when you're walking down the street'.

In spite of these difficulties, respondents made efforts to create supportive communities. Some contemplated change. They considered joining a parent group to get adult support, or thought about joining a new church. Several people identified spending time with and staying connected to friends as something that kept them well and buffered them from the hospital. A few described day treatment as having served that role – having provided both structure and community – something they now needed to replace. In some instances, respondents made decisions that required hard choices. They severed themselves from mental health services that they associated with 'being sick' and joined card clubs, single's groups, an orchestra, or book clubs – often in church settings, instead.

A sub-theme of community integration is normalcy. Respondents reported their desire to do the 'normal' things that distanced them from the

mental health system and the societal stigma of mental illness. Participation in various community activities was a highly valued avenue and seen as a path toward normalcy. As one person commented, 'Doing normal is being normal'.

Reintegration with Family and Friends

As clients' symptoms improved, reconnecting with family and friends became a significant task. The emergence of this task often coincided in time with the case manager's use of family and friends to assume some of the supplemental functioning that the case manager had previously provided. Respondents indicated that friends and family supported them emotionally and often financially. Family and friends also served as people who could help respondents to 'reality test', which meant to let respondents know when they were doing well or getting ill again. Respondents noted that 'my friend reads me like a book', 'My mom knows me real well'. One woman described the significance of her family's understanding her mental illness: 'I've had excellent family, and they caught it early'. Friends were described as people who helped respondents access more resources and achieve greater independence. They helped 'signing up for social security', 'I have this friend that like takes me to the boondocks and lets me drive . . . taught me to parallel [park]. Yeah.' These activities helped respondents reintegrate into the community. Parents might also serve as a bridge by acting on behalf of their children. One mother co-signed for her daughter's apartment so she could live on her own again. 'The only reason I think that lady accepted me is 'cause my mom was a co-signer. And you just can't reject my mom. None of them could'.

Reconnecting with family was not without conflict. Respondents described that the initial comfort they felt by living near or with parents when they were more acutely ill and how the sense of comfort changed. 'At first it was really cool, but it became a struggle as my parents and my sister − treat me like I'm four a lot'. Respondents were aware that their family was ambivalent about what might be possible for them. For example, the family might vacillate between 'you're 24 now, do something' and 'the rest of the year, "oh look at, look at the pretty picture you made", like something in day care'.

Many of the respondents' accounts suggested that family members felt burdened, i.e. negatively impacted by a family member's mental illness. Respondents pointed to both strained and lost family relationships. One man described this loss as 'an empty spot' or a 'super loss'. He stated, 'I don't even think you could fill that void with a new family'. Others described parents who had temporarily helped them, for example, to manage finances or separate from a 'bad roommate' but now had difficulty giving up these roles. Respondents observed that although parents or other family members took on giving more help, they were simultaneously (1) resentful about giving that help and (2) reluctant to give it up. Respondents wished that these family members

could slowly step back and allow the person to assume more self-authorship or agency in his or her own affairs. This desire reflected the importance of pacing one's own recovery, which is a theme that runs through the recovery process.

Finally, those respondents who were themselves parents noted that there were complicated dynamics associated with reassuming the role of parent and adult leader with their children as they got better. These parents were particularly struck by their child's neediness. Children might be unusually clingy or simply want a lot of time with their parents, in the spirit of rebuilding some attachment. One mom described how her children continued to behave even though a year had passed since she was acutely depressed. 'When I am around, they have to be right by me. Like today's my day off [but] they were in my bed at 6:50. If it was my day to go to work, they wouldn't be out of bed until 7:30 or 8:00'. She went on to relate that her kids' rooms were unusually messy since the children had moved out of her mom and dad's house and again had spaces of their own. She explained that their messiness was connected to the fact that her children had felt a high expectation to be on their 'best behavior' while living at their grandparents, with their 'things under their beds'.

Another parent reported being deliberate in the steps she took to re-establish both the relationship and her authority with her children. She noted how 'I've been trying hard to spend equal time with each one of them out to lunch or out to dinner . . . so they feel special'. Reintegration with one's own children, however, was not always smooth. Parents described kids who noticed when they were still not 100 percent. 'Mom, you're not listening. Don't you care?'. Parents themselves noticed the consequences of their mental illness and their ability to be present with their children. 'That's why they're acting up more. I can physically tell when I'm not able to be there totally for them'. Some described their kids as acutely attuned to their mood while others pointed to the invisibility of their illness to their child. 'My kids don't think I'm depressed. They just think I'm pretending'. Parents consistently described the process of reintegrating with their children and reassuming leadership as rocky and gradual – a process that must be carefully paced. This process often involved both worry and hope. Parents claimed that they had a strong wish for support from other parents facing normal parenting issues, outside of the mental health system, and for a chance just to be with other adults who have children.

Reintegration with family and friends was complicated. Respondents had needs for assistance and independence but noted that family members grappled to find their own role in response to these needs or manage their ambivalence about respondents' abilities and how much help they actually needed. Parenting was a demanding task as respondents noted their children's reactions to the residual effects of their illness, their children's needs for reassurance, and the problems they faced in re-establishing their parental authority.

Reintegration with the Case Manager

Respondents overwhelmingly rated their case management experience positively. They felt very connected to their case managers, often more than the case managers themselves may have realized. Several respondents described case managers as like family and friends noting their strong attachment to them. Respondents often indicated that although they were better and more capable of being on their own, they also were reluctant to give up case management. Indeed, several of them had strong feelings about ending case management. One woman described the prospect of ending with her case manager as analogous to losing a father figure. '[He's] not old enough to be my father or anything. But it's kind of like he's my father if I need help or something he'll be there for me. So it'd be kinda like losing that. It'd be kinda like losing your father or something, kind of like, somebody that you can depend on'.

Even those respondents who planned to terminate case management expressed gratitude and ambivalence about ending. Because the case manager provided a sense of constancy or stability, many respondents expressed the wish that either the case manager could be available in the background in some way if support was needed or simply, that they could call the case manager occasionally to maintain contact. A few respondents just wanted to forget this time in their lives and move on. Most, however, remembered being worse than they were now. When they looked back they saw both disjuncture and progress. They also imagined greater possibilities for themselves in the future.

Not everyone planned to terminate case management services. A significant subset (20%) had ongoing relationships with case managers that they did not anticipate ending. They clearly did not see their need and this decision as indicative of failure. Rather they viewed the ongoing presence of the case manager in their lives as a comfort. These relationships tended to be framed positively throughout the course of case management, with a noted absence of conflict in the second year of treatment.

Although respondents spent time contemplating the future of their relationships with case managers, they described that neither they nor their case managers initiated much, if any, discussion about termination, even in long-term working relationships.

Reintegrating Self and Illness

Respondents frequently reflected on their experience of being mentally ill. They considered the ways their illness had impacted on their lives, where they were now, and the meaning of their experience. They described things they did in the past, the shame or embarrassment they felt about these events, and the questions they had about how to handle the consequences of behavior related to their illness. Events might include financial costs associated with a manic episode, or strained relationships from a period in which the person was

psychotic, dependent, or aggressive. Other respondents wanted to understand and compartmentalize 'what happened'. That is, they sought to remember with some distance and perspective the things they did that now embarrass them. In addition to making meaning out of what had happened to their lives due to illness, respondents began to focus as well on coping with the attendant shame, internal stigma, grief and loss.

One man recovering from a manic episode described this process as a 'shame attack':

> I get . . . shame times where you get a memory of something you feel is pretty shameful like of an illness attack . . . And instead of saying 'Oh my God, you're a freak, you'll never be able to tell anybody this, you better make sure you don't say it out loud' . . . finally I can look at myself and say 'poor thing, look what you had to go through'.

He went on to describe the internal and gradual process of learning to forgive himself for his past behavior as part of learning that he need not be defined by his illness. He described thankfulness for a therapist who saw him first as a person, as someone *with* a disorder rather than fundamentally 'disordered'. In his descriptions, he experimented with using works that helped make the illness event smaller in the scheme of life, externalize it or give it less of a place in defining who he is today.

These issues were experienced by all people in their own unique way. One woman described her struggle with who she is and what can she do: 'on some days I feel really good and I think "I'm not mental. There is nothing wrong with me" four, five days go by and I'm convinced I'm over it. Then I get sick again. It's hard when you don't know what you can do day to day'.

An older woman who had been severely impaired with paranoid schizo-phrenia illustrates an exceptional reintegration of self and illness. She said:

> Everybody has an A column and a B column, the good and the bad. I've learned to focus on my A column. I still have voices but I don't let them run my life. When I get to feeling sorry for myself I just get off my pity pot. I go to church, visit family and I spend a lot of time on the phone helping my friends. I'm like the Marine Corps. I am the best I can be.

Respondents' efforts to reintegrate who they are with their illness required acceptance and the establishment of understanding and perspective in relationship to the past.

Barriers to Community Integration
All respondents indicated a desire for more social connection and inclusion in the community. They aspired and strove to be seen as whole, functioning people

who have something to contribute as opposed to people who only receive services. One person commented, 'If you want health and wellness, you gotta have us be able to be in the community'.' Respondents searched for a wider social network, and one they perceived as 'normal'. They enjoyed knowing the people in their apartment buildings, being a part of a card club, displaying art, playing the piano, and just having friends. People who achieved this level of inclusion seemed to being doing much better. Respondents often wondered where to find normal, social contact. One woman described her struggle. 'I have one friend [and] she's in detox. So that's it. I don't know anybody. That's kinda hard, too'. Another described the hospital as a place 'where my security was'. Because social connections were hard to establish, respondents often turned to their relationships with case managers who became central in importance even serving as a substitute for friends or family.

Besides the struggle to find and make friends, respondents perceived the lack of money and transportation as significant obstacles standing in the way of achieving greater independence. Many, in fact, equated having more money and accessible transportation to independence, power, agency, and meaningful community involvement. One woman explained that she needed the bus to get to museums and movie theaters because these resources did not exist in her economically poor neighborhood. Another man declared, 'Your destiny is controlled by a bus. You know, with a car, you can just start it up'. Respondents saw better transportation as an avenue to better jobs and more social involvement. Most contended that the fact of being dependent on a bus, particularly for those living in the suburbs, contributed to their feeling demoralized and more dependent generally.

The vast majority spoke about financial binds. For example, some respondents could not afford the insurance to drive that was required by the state. Others could not work enough to afford the cost of leisure activities. Respondents further commented that the rigid requirements associated with financial assistance kept them trapped. For example, if they returned to work, they would loose their health insurance, housing assistance, and funding to finish school. One woman explained, 'Daycare is like $800 a month, and I only make $200'. People described financially 'living on the edge'. A significant number were not getting by on the money they have. One respondent shared, 'I only get $40 in food stamps. You know, that's not nothing. Sometimes I have to go to my mom's for food'. As with feeling dependent on the bus, respondents claimed that the lack of money interfered with their recovery because receiving social security kept them dependent upon a system from which they wanted emancipation. 'I know as long as I'm a part of the system, I won't really be independent'. Concretely, it kept many of them in low paying jobs from which only more education could help them escape. 'Without college, unfortunately, all the wages are very low'.

Limited opportunities for finding 'normal' social contacts and a necessary dependency on public transportation and social security are barriers to mobility, employment opportunities, and social inclusion of respondents in their communities. In addition, respondents felt trapped by conditions that eroded their efforts to become more 'normal' and independent.

DISCUSSION

This study reports the results from the third year of a three-year longitudinal study of the lived experience of persons with mental illness who are participating in community case management services. These findings validate and add to previous literature that has identified macro level obstacles to social inclusion for persons with severe and persistent mental illness. Few previous studies, however, have used longitudinal designs that allow for a focus on the process and greater specificity for each time period. Consequently, the results from the third year of this study build on the findings from the previous two years: namely, (1) demoralization, the experience of being overwhelmed by disability and the attempt to get some degree of control over the illness in the first year of recovery and (2) the development of mastery and coping with the consequences of illness in the second year of the study. The uniqueness of this study is that it describes and contributes to the evolving picture of the recovery process and specifics of the experience of persons' attempts at social integration.

During the third year of recovery, respondents in this study made significant improvement and strongly aspired to participate in non-ill communities and activities. At the same time they continued to struggle with stigma and unmet needs, which included housing, money, lack of transportation and few opportunities for social inclusion. Efforts to reintegrate with family and friends brought challenges due to the impact of mental illness on family relationships, changes in roles, and the perceived instability by family members of respondents' gains. Positive relationships with case managers became more ambiguous as respondents' abilities to manage independently grew. There was a marked lack of discussion and clarity about the need for or fact of termination, which left the extent and ongoingness of the relationship unspecified.

The theme of self-reintegration, while briefer than other themes, emphasized the work needed to become less engulfed in a mentally ill identity. The ability to look at one's experience of illness and the impact on one's identity appeared to be grounded in the experience of increased mastery and control over the illness. As a result, respondents described that they began to wake up to the consequences of mental illness in their lives. They were fearful of relapse, concerned about their social image, and struggled with two essential questions, 'what can I really do?' and 'how do I understand what has happened to me?'

This work was done in bits and pieces and allowed people to make meaning of their illness experience.

Despite their best efforts, however, the barriers to inclusion remain, as evidenced by lack of access to the community due to limited social contacts, money and transportation. Although boldly set forth as a mission by the US Commission on Mental Illness in 1961, the dream of community integration 40 years later has not been fulfilled.

Implications for Practice and Policy

Findings from the third-year study highlight unmet needs at the micro and macro levels of case management practice that could facilitate greater social inclusion for people in recovery from severe and persistent mental illness. A list of the essential themes and client and case manager tasks are found in Table 2.

For Theme 1 (reintegration into the community), case manager tasks involve the identification of disjunctions between the client's past and present social position and advocating for services to help bridge the gap and meet basic needs. Advocacy also includes the development of new services for unmet needs such as supported socialization that pairs community volunteers with clients. In addition, case managers facilitate social connectedness by developing clients' social skills.

For Theme 2 (reintegration with family and friends), case manager tasks focus on dealing with family relationships by the management of potential conflict including mediating disagreements, the facilitation of role transitions between clients and family members, the establishment of boundaries between family members to reduce family burden, and the development of parenting skills.

For Theme 3 (reintegration with the case manager), case manager tasks center on the feelings and fears of the client including ambivalence about ending and a clarification of the terms for a successful termination, if appropriate.

For Theme 4 (reintegration of self and illness), case manager tasks are concentrated on helping clients make meaning out of the illness experience by reviewing the impact of the illness on their lives. Case manager tasks include helping clients gain perspective by grieving losses and uncovering and processing shame-laden events.

For Theme 5 (barriers to social inclusion), case manager tasks require advocacy, referral and resource development to improve access and remove obstacles that stand in the way of greater independence. Theme 5 also highlights social justice, which is a defining concept in the social work profession. However, the SPMI population has barriers to social inclusion that have often not been clearly identified as a social justice issue in social work. At the macro level of practice, therefore, social work roles focus on policy development and class and community action to promote social justice for inclusion of persons

Table 2 SOCIAL REINTEGRATION ISSUES AND TASKS

Theme/Issue	Client Tasks	Case Manager Tasks
1. Reintegration in Community • Experience of disjunction of social position. • Intentional steps to reintegration in normal social networks.	• Contemplation and change activities. • Pacing recovery.	• Advocacy. • Services development. • Facilitate role transitions. • Improve social skills. • Contemplation and change activities.
2. Reintegration with Family • Experience of disjunction of social position. • Receive support and help. • Conflict and ambivalence. • Regaining parental role. • Loss of family.	• Establish boundaries with family. • Cope with conflict and ambivalence. • Grieve loss of family. • Develop parenting skills.	• Support & problem solving. • Grief work. • Family work/education. • Advocacy. • Parenting support. • Respite care.
3. Reintegration with Case Manager • Positive alliance redevelops. • Termination: loss of relationship not discussed. • Subgroup continues with positive alliance and ongoing service.	• Identify and express feelings/fears of ending.	• Discuss termination plan. • Attention to feelings/fears. • Develop backup plan. • Admire achievements. • Positive alliance.

Table 2: continued

Theme/Issue	Client Tasks	Case Manager Tasks
4. Integration of Self & Illness • Able to look at experience of illness & make meaning of it. • Deal with shame & stigma. • Attention to feelings/fears.	• Identify & discuss ways of understanding self & illness. • Deal with shame & internalized stigma.	• Focus on meaning-making of illness experience. • Person with illness. • Stigma reduction.
5. Barriers to Social Inclusion • Housing. • Transportation. • Education/ job opportunities. • Money. • Social stigma.	• Identify priorities. • Communicate needs to case manager.	• Advocacy. • Referral. • Resource development.

with severe and persistent mental illness into community. Policy initiatives at all levels are specifically needed in the areas of housing, transportation, work, and parity in mental health funding. These four areas provide the essential resources that must be in place in order for persons with severe and persistent mental illness to have genuine opportunities for social inclusion. Class advocacy, for example, is needed to promote increased access to public transportation or programs that would provide transportation on an individual basis to required services. Class advocacy is also needed to increase low cost housing options including incentives to landlords to rent to persons with SPMI. At the national level policy initiatives are needed to change social security rules that allow for a graduated increase in work hours without the loss of health insurance.

Limitations

This study was limited by the fact that qualitative findings cannot be generalized beyond clients who participated in this research or the socio-historic time when they were interviewed. Moreover, themes were not corroborated by the participants in this study due, in part, to the longitudinal nature of the study, transient living arrangements and instability of the mental health of this population. Themes from the first two studies were corroborated by the case managers from the non-profit mental health agency used in the research. Themes from this study have been submitted to case managers for corroboration as well.

CONCLUSION

Recovery for persons with severe mental illness is an evolving process. This third-year study of the experience of recovery found that in spite of their best efforts, the social context puts extraordinary limits on what clients are able to do. Respondents in this study were ready to reintegrate socially but had trouble finding a place because of the community's response to mental illness and respondents' unmet needs. The findings from this study, however, delineate tasks for case managers and social workers generally to attend to, that can facilitate clients' abilities to move successfully back into the community as well as policy recommendations to achieve greater social justice. This article integrates the voices of consumers and the experience of social workers. Particular tasks and needs are clarified and integrated with micro and macro options to provide a full picture of the needs of people with SPMI.

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