Others: The Role of Family, Friends, and Professionals in the Recovery Process

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Relationships have a tremendous impact on how people recover from schizophrenia. Previous research has focused on the role of clinicians in these supportive relationships, but the current study finds that these relationships can occur within the mental health system, the family, or out in the community. Regardless, it is very important for people in recovery to feel as if they are supported and cared for. In qualitative interviews, we examine the specific aspects that characterize other people’s actions when helping in the recovery process. First, for both professionals and family members, being “there” and available seemed to help people in recovery. Secondly, people helped by doing more than was expected of them, sometimes by lending money or doing something extra to help out the person in recovery. Thirdly, people helped by doing something different than what was expected of them. For professionals, this might mean that they break a minor rule. These factors helped people in recovery feel like they were special, chosen, and “worth” doing something extra for.

The majority (60–70%) of individuals with schizophrenia do not marry, and most have relatively limited social contacts. (APA, 1994, p. 278)

In this article, we focus on the social relationships described by the informants in the multinational study described in more detail in the previous special issue of this journal (Davidson, Borg, Marin, Topor, Mezzina, and Sells, 2005); relationships with a range of

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people including, but also going beyond, family and mental health professionals. In this way, these findings challenge one component of the conventional clinical wisdom about psychosis: that is, that people with psychosis prefer to be alone.

BACKGROUND

People with severe mental disorders are often described in the psychiatric literature as being withdrawn and isolated. Hatfield and Lefley (1993) summarize this widespread image: “People with schizophrenia are seen as unsocial, eccentric, suspicious and solitary. They have poor empathy with other people, are rigid in behavior, communicate in unusual styles, and prefer to be alone” (p. 62). This isolation has been thought to characterize schizophrenia itself, rather than being perceived as a consequence of the social conditions under which many people with mental illness live—namely, stigmatized and impoverished. This alleged inability to enter into interpersonal relationships has a long tradition in various schools of thought in psychiatry. Kraepelin (1971), for example, described dementia praecox as a disorder in which the individual as a person virtually ceases to exist: “There are apparently two principal groups of disorders which characterize the malady. On the one hand we observe a weakening of those emotional activities that permanently form the mainsprings of volition. In connection with this, mental activity and instinct for occupation becomes mute” (p. 75).

If the individual ceases to exist as a person, then companionship and social relationships also cease to be possibilities. It means not only that people with severe mental illnesses withdraw from social relationships, but also that they are not affected in any goal-directed and predictable way by their experiences or by how others respond to them. In other words, the human interaction involved in psychiatric treatment is ineffective in bringing about improvement. Family, friends, and personnel in psychiatry or the social services, whether or not they have any therapeutic training, can have no positive effect on the course of the illness. They may enhance the person’s quality of life or even contribute to ensuring that the functional disability caused by mental illness does not become a handicap, but they cannot affect in any way the disorder itself.
It is mostly in sociology (Barham, 1984; Bentall, 1990; Goffman, 1961; Scheff, 1984) and in the sociopsychological literature (Estroff, 1985, 1989; Mead, 1974; Thomas, 1997) that attention has been drawn to the importance of other people in the lives of people with mental illness. Bury (1982) described chronic illness as a biographical disruption. The individual’s life is divided into a “before” and an “after.” In between, an inexplicable event has occurred that has disrupted the continuity of the original biographical narrative. When a problem situation has persisted for a longer time, the individual’s social environment begins to adapt itself to the new circumstances. Memories of the individual’s earlier life begin to fade and there are fewer people in the person’s surroundings that are there to remember. The person’s social network gets smaller in number, and there are fewer people who knew the person from “before.” There is also a qualitative change in the network; people who came into contact with the person in the period “after,” and, as a result of the person’s problems, have now replaced his or her former friends and family. They relate to the person because of his or her problems without knowledge of his or her past existence. These two processes tend to reinforce the feeling that a severe mental disorder is an “I am-illness” and not an “I have illness,” and thus constitutes a permanent change (Estroff, 1989). The diagnosis is something the person has become, the person’s new identity, rather than an illness the person has contracted. This shift in perspective is commonly found among both people with psychosis and their social networks.

Earlier recovery research (Breier & Strauss, 1984; Davidson, 2003; Davidson et al., 2001; Denhov, 2003; Topor, 2001) indicates that other people can in fact play an important role for persons who have a severe mental illness. To shed light on this finding, the present contribution asks the following questions: (1) Can other people contribute to the recovery process? (2) If so, which people? and (3) What, according to the informants, is it that these people do that contributes to the recovery process?

METHODS

The methods utilized to collect and analyze the data for this multinational study were described in the first article in this series, in the previous issue of this journal (Davidson, Borg, Marin, Topor, Mezzina, and Sells, 2005).
FINDINGS

The empirical data collected through the 12 interviews in this study indicate that people with a diagnosis of severe mental illness both desire and are capable of entering into reciprocal relationships with other people, and that they are aware that those relationships change over time and as a result of their illness. Specifically, there are three findings that point to this conclusion: (1) social relationships play a central role in the recovery process, (2) a beneficial social relationship is not dependent on the helper’s formal education or training, and (3) beneficial relationships have certain common characteristics. We will briefly describe these themes before examining more deeply the specific nature of the relationships.

The Importance of Relationships

All 12 informants describe themselves as being involved in relationships with others. During acute phases of their illness these friendships might be broken off, either by themselves or by the other person. But when the acute phase had passed, most of the informants said that they made a real effort to recreate their former relationships or try to form new relationships if their old social network had thinned out too much. Several of the informants talked about their loneliness as being a consequence of the stigmatization process, rather than as reflecting some trait within themselves. Ole described the stigma he felt at the beginning of his illness:

... I had sporadic contact with friends at that time... It was very important for me to be seen or accepted, like. And I was very honest about my illness then—right away when I realized that—I started on medication—I was ill, I wrote to all my friends that this was what had happened... But I didn’t understand what being ill meant—neither did they—but the reason I was so eager to keep in touch with my friends was that I wanted to be comforted, like, but I didn’t get that kind of response...

For many of those interviewed, the feelings of loneliness and isolation were extremely painful, and not only pointed to what had been lost in the course of the illness but also increased the trauma of the illness itself. In response to this, several described how they learned to change the nature and intensity of their relationships in order to protect the people in their lives from the full brunt and severity of the illness, and thereby maintained a social network.
All of the informants talked about their relationships playing a major role in the course of their illness, and in their recovery. Many considered that their psychiatric problems were directly related to their personal relationships. They mentioned, for example, the relationship with their parents and the problems they often had in contacts with the opposite sex and with friends. Many also claimed that the humiliating way they had been treated by professionals, family, and friends had led to a worsening of their problems. In such a context, withdrawing from relationships was a way to manage a situation that constituted a real risk for the individual’s mental health. Ole continued his studies at the university while he was still psychotic. In order to cope, he had to spend less time with other people, which his parents accepted: “I was sort of allowed to keep to myself when I slept through those six months. There weren’t any demands on me, like you have to get up now and eat. I was allowed to do it and this has probably helped me a lot.”

All the informants described critical phases in their recovery process that were directly related to their meetings and interactions with other people. Sometimes they were the same people, usually family members, who had earlier played a negative role in their lives.

Among those whom the informants indicated had contributed to their recovery were professionals, such as therapists, nurses, social workers, and psychiatrists. Their contribution did not seem to be connected to any particular theoretical school; it was not their formal competence that was brought forth and described as being of importance. What appeared to be important were their personal characteristics and the type of relationship they succeeded in establishing with the person. And, in fact, people outside the professional community were described as being able to play a central role in the recovery process. Parents, siblings, friends, and peers, for example, are mentioned in the narratives.

As a group, the people who contributed to the recovery process can be characterized by their heterogeneity. We will now investigate some of the characteristics of the beneficial relationships that are described in the interviews. Since relationships with other people in recovery are described elsewhere in this issue (in Sells et al., 2005) we will concentrate here on the informants’ relationships with their families, friends, and the professionals with whom they interacted.
Relationships with Family and Friends

Three aspects of the contribution that family members and long-time friends made to the recovery process emerged in the data. We have termed these “standing alongside the person,” “being there for the person,” and “moving on with recovery.”

Standing Alongside the Person

Because they had a relationship with the person before he or she became ill, people from the past have certain knowledge about the person as an individual. They can bear witness to the fact that the person has not always had a psychotic disorder. By standing by the person in good times and in bad, they can confirm the person’s complexity. By “being with” they: (1) Stand for a continuity that extends back into the person’s preillness history, (2) Demonstrate by their very presence that the person cannot be reduced to the stigmatized image of someone whose whole make-up consists only of symptoms and shortcomings, and (3) Are the bearers of hope for a future that differs from a present life marked by suffering and limitations.

Continuity in a life-long perspective is essential, and even a professional can acquire a special significance as someone who has known the person in different periods of his or her life. Carol describes what it meant for her to have a case manager who knew her in her earlier life:

Carol: This case manager was the only one who was really pushing for recovery with any of the consumers.
Interviewer: So it’s good you got a hold of her?
Carol: Yeah, yeah. And it just happened that I had known her from when we had gone to school, which I think also helped a lot because we had an almost personal thing going because of knowing each other from previous years.

Standing alongside the person means that he or she can rely on the family member or friend’s strengths, expectations, and knowledge when times are difficult; the person is not alone in the world. Parents, siblings, and one’s own children can be reason enough for not taking one’s own life for someone who has touched bottom. During times when problems accumulate and one has lost all hope, a person can still choose to survive for someone else’s sake. As Carol describes: “The other thing that kept me going the first time I thought about committing suicide is... if I killed myself what
would happen to my sister?’ That someone else would be affected by one’s death can be reason enough not to go through with plans to commit suicide when there seems to be no other reason to not do it.

**Being there for the Person in Recovery**

Having to live with a severe mental problem creates enormous difficulties when it comes to trying to cope with daily life, whether in the psychiatric system or beyond. It is in such problematic situations that family and friends can play a crucial role. They might be the first ones to notice that the person’s problems are getting worse, and thus they could be a connecting link to care. The informants sometimes described their interventions as an infringement on the individual’s rights, but also as invaluable help. It also can be difficult for people to make their voices heard in the psychiatric care system, and to demand that their rights are respected. Here, family members and friends can intervene as advocates and lobbyists on the person’s behalf. By intervening at an early stage they may be able to prevent an eviction order against the person or deflect other serious social consequences. They can even make sure that the person is treated as a citizen whose civil rights entitle him or her to the basic requirements for a decent life.

Many of our informants describe how family and friends have helped them manage these practical problems. That people with a severe mental disorder have to contend with many socioeconomic problems is a well-known fact. Even in countries with a well-developed social welfare system, the benefits paid out to people in recovery can be very meager, because many have not had time to work (and thus pay into the social service system) before becoming ill. In countries without a social insurance system, economic circumstances can be even more difficult. Many of our informants had problems obtaining or retaining a place of their own to live, making enough money for clothes and food, or affording social activities, like movies or eating out. Sometimes the help of family or friends helped prevent the person from becoming totally destitute, enabling him or her to retain some financial independence and dignity.

The practical arrangement of living in one’s parent’s house is one example of concrete help. The situation can be highly emotionally charged as well. Ole describes how his economic and social lives were intertwined when he was living with his parents:
Living at home—for one thing it means safety and for another it’s social, something going on, for otherwise … I can’t stand the thought of not being able to live at home, of sitting in a flat somewhere all by myself—without a social network. It takes time to build a social network. I’ve spent several years doing just that, just letting it turn into something that I can be comfortable with.

Bernice touches on the same theme when she talks about living at home with her mother:

I moved back home because I wanted to save money and my mom is more, you know, she’s not like standing over me or telling me to do this, do that, do this; we get along fine, no problems. So far it’s not been a year yet, but if I have any problems, things like that, I basically let her know in some way that I have a problem or something like that, so it’s, it’s going good. She’s happy I’m at home. So it’s going good.

As with Bernice and Ole, being at home is at once being needed and being protected, allowing them to concentrate on other aspects of their lives.

Recovery as a Social Process
The unique and personal nature of the recovery process has often been pointed out in the literature (Anthony, 1993; Deegan, 1996). This is a finding in our own study as well. At the same time recovery happens on an individual level, it is evident that the recovery process is social as well. Part of recovery is recognizing the reciprocity between the person and his or her social supports. Carol describes learning to rely on others for help:

Before, I used to feel that I could do everything myself; that I didn’t need anybody to help me. It was always drilled into my head that nobody was ever going to take care of me; and it’s not that people are taking care of me now, but I know now that I’ve got people out there who care about me and are willing to help me, like if I have a tough decision to make. People are willing to help guide me down the right path.

During the recovery process, the person’s dependence on certain kinds of interventions decreases while the capacity to contribute to the well-being of others increases. As is commonly the case, family members, once deemed only as “next of kin,” stop being “next of kin” and become once again brothers and sisters, fathers and mothers. Their identity is no longer defined in terms of their
relationship to a person with a severe mental disorder. Carol talks about rediscovering this relationship with her sister:

I raised my sister and until about a month and a half ago I was still—I was wondering whether or not my sister wanted me around. And I found a note from her and the note actually said that she and her husband couldn’t have accomplished what they did if it wasn’t for my help and that she loved me for everything I’ve done for her, and I had gotten that note from her but never really read what the note said, and I’ve had that note for three years. I read the note many times but never really realized what it said until about a month and a half ago. I was talking with her and she says, I’ve told you that many, many times, and I say I never heard it.

Carol is reminded of her own capacity and of others’ dependence on her and her continued existence. Their relationship becomes reciprocal once again and is a confirmation that she cannot be reduced to simply a collection of symptoms.

That a person recovers means that other people in his or her surroundings also have to recover; the unequal dependence relationship that was established between the person and his or her social network during times of deep distress must change. The helper must step down from this one-sided role and be prepared, not only to disengage, but also to perhaps now be the recipient of the person’s concern and advice. Although everyone involved desires the recovery, they each have to face certain challenges. Franca talks about the difficulty in negotiating the relationship with her mother:

I found myself all alone with a very difficult relationship to my mother—who had understood immediately that I needed my freedom, which I give her credit for—but a mother who even now, every so often there is tension because she’s still relatively young and very active, so there’s an element of, not competition between us but, well, in short, she has a very strong character and wants to meddle in my life.

New acquaintances that one has made after coming into contact with psychiatry can also contribute to recovery. Contact with others who have mental illness can generate a fear of having to live as a “chronic mental patient,” a fear of life-long suffering and dependence on support from psychiatry and the social services. But contact with others in recovery also can lead to a kind of fellowship in which it is not necessary to explain oneself or apologize for one’s problems or for one’s strange experiences (symptoms and ways
of interacting with other people) and shortcomings, offering an immediate sense of acceptance and being understood. Ole relates:

I started going there and met people who were in the same situation as me. That was the first time I ever met people who were ill, and that was a very positive experience for me. Because you were accepted and seen, you know—I liked that a lot. I got some friends there and experienced something that was really positive and that was being with other men.

These experiences can form the basis for new relationships that extend beyond the sphere of mental problems and psychiatry. Franca describes:

I’ve created a whole new network of friends, and with my cousin as well, apart from our blood-tie, our kinship, I’ve also established a deep friendship with her. We call each other almost every day, and if I have a problem it’s easier to talk with her than with my mother, for example. And then, there is this group of friends at the Centre, women friends; this has also grown a lot in the last three, four years, this being together. We would read texts that I or a friend of mine, who was also part of the group, suggested, in those last years when I was still teaching. Every day, after a tiring day at work, I’d go there and I’d ask myself each time: Am I going to be able to get on a bus and go to [name of the mental health centre] this afternoon? And then afterwards I’d come out of these gatherings feeling much more relaxed and rested, feeling better.

It is through interactions with others that we get a reflected image of ourselves, a self-image that is based on having something to give the other. Ole describes how important this interaction was for him:

And one thing about the women there is that they really care about you at the day center. I have very good contact with some of them and I think I’ve meant something to them, too. They sort of cared about me, and it isn’t like that at home, so it was very positive that they saw you and kind of accepted you. I experienced that as being really unique. It meant a lot to me.

Interacting with others who have similar experiences in settings that are not marked by psychiatry can be a source of hope. The illness need not be chronic. As Bernice explains, the others serve as indisputable evidence that change is possible:

When I started Advocacy Unlimited, um, before I didn’t even know the word recovery or, you know, I didn’t know that they exist, basically.
Meeting people and seeing people you know doing positive things; people in recovery just freaked me out a little bit. It was like: ‘Wow!’

In some cases, recovery requires that some people will have to leave the social network and new ones come in. Forming relationships with people who are not involved with psychiatry is a kind of confirmation that recovery is in progress. In Franca’s case, her initial contact with psychiatry occurred at the same time as her husband left her. In the interview she talks about an aspect of the recovery process that is seldom mentioned in the literature:

This love relationship [with a new man] also helped me a great deal from a female point of view, as a woman, in the sense of making me feel desired, having a sexual relationship, having a complete life… We’ve been together now for nearly 10 years, but we always keep our own freedom, our independence.

Such relationships mean that both parties accept the person just as she or he is and they accept the personal history that the person brings to the relationship. This is the ultimate confirmation that the person has a value beyond his or her psychiatric history.

Relationships with Professionals

Professionals can play an important role in the work to recovery. The professionals described in our interviews did so in three ways: (1) they conveyed information to the person because of their formal position as a professional and by virtue of this expert status or served as an intermediary for various interventions that involved money, activities, groups, housing, and occasions for socializing, etc.; (2) they did more than their formal role required; and (3) they did something different than what the person had come to expect from professionals.

Formal Position as a Professional

In several narratives, professionals played a major role simply because they were professionals and were thus assumed to have expert knowledge. Because of this expert knowledge, the person may have had greater confidence in what the professional said than in what others said. The professional was thereby someone who
functioned as a waypoint; a point of orientation between hallucinations and “reality.” Luca explains how his clinician helped him to make sense of his delusions and hallucinations:

Interviewer: Let’s talk about something that I think is important, I mean your governing, dealing with, confronting, understanding—I’m not sure which term to use—the symptoms that this disorder brought on. How did you get over them?
Luca: But they said they were hallucinations... I wrote a kind of report about what I felt, what I didn’t feel, what I supposed, what I didn’t suppose, and based on that I drew my own conclusions. I accepted that my conclusions were wrong and so I... in the sense that I don’t feel anything anymore...

Interviewer: And what were your conclusions?
Luca: Oh, I don’t know, I thought things were conspiring against me, but they told me that it wasn’t so, and I accepted what they said.

For many people, what the professional says and does bears more weight because it is based on special training, knowledge, and practice. Annica takes up the thread of this formal training when talking about several of the professionals she considers to have helped her. She feels that formal education is a guarantee that they will understand her: “She understands me, but she’s trained for that. She has trained to be a nurse, she’s trained in psychiatry. That’s how she has the kind of knowledge that an ordinary person in working life doesn’t have.”

Formal competence and training seem to have given the informants a feeling of security and safety. Even if a clinician says and does what others in the individual’s social network also say and do, the clinician’s words and actions are accorded more significance and gravity. The professionals also have access to certain resources which, when made available to people, can create new opportunities for them, as Luca describes: “And the fact that they (the Center) supported me with this activity I’m doing now. I mean the job-training grant that they pay to a social co-op, which gives me a little job.”

Doing More Than is Expected
Having specialized training and access to opportunities and resources is important in strengthening the relationship between
the clinician and patient, but wasn’t sufficient in building trust and confidence; most informants also talked about the importance of clinicians or other professionals going above and beyond what is expected of them. To do more meant that the professional did what he or she was employed to do, but performed these tasks so thoroughly that the person sensed that something unusual had occurred and felt the professional had gone above and beyond the job description. In the interviews, two themes reoccur in relation to this issue: (1) receiving more time, more attention, than the person came to expect on the basis of earlier experiences; and (2) being chosen and given special treatment by another person. Mia gives an example when she describes her first meeting on the psychiatric ward with a mental health worker who was to be her contact person:

Interviewer: Why did you choose him that morning?
Mia: He was so nice. He’s the kind of person I’ve never had contact with before. That was what I was thinking at the time.
Interviewer: What did anyone have to do to be nice to you back then?
Mia: Sit down and drink coffee with me. Don’t be in a rush to get away. Have time to listen…That’s what I needed then. There was no rush. And when I had finished, after we had a meal together, and I took my plate away, he was still there when I came back. And so we talked a little more and it was his turn to close the kitchen, and after that we went to my room and talked some more. That suited me. That’s how I want people to be. It was so nice and cozy.

The mental health worker gave Mia time, with two key dimensions: amount and quality. In a setting where time is usually both limited and scheduled or planned in advance, the extent of the mental health worker’s availability was in sharp contrast to Mia’s expectations of him. By choosing to remain with her, he chose her above all others. The importance of being chosen and accorded special treatment is an important component of those situations where the professional is described as having been helpful.

**Doing Something Different**

Receiving more and being chosen are important, but doing something different (perhaps even doing something beyond the rules of the institution) appeared to be equally important. Many of our informants described the differing beliefs among staff members working in the same unit regarding what kind of relationship *should* exist
between patients and staff. These divergent traditions were fixed in
the regulations, routines, and attitudes that permeated any institu-
tion’s rhetoric and practice. In the depictions of the actions of pro-
fessionals who have been beneficial, we heard time and again of
professionals who accepted gifts from their patients and who took
various initiatives on their patients’ behalves that are not directly
required by their psychiatric conditions. That the professionals
themselves found something of value in the relationship with
the person seems to be a key element. People in recovery learn
to distinguish between different kinds of personnel, as Kari
explains:

Interviewer: Can you give any examples of what you valued in your
relationship with that special nurse you had for many years?
Kari: We got close and she was almost like a friend, and then I made tapes
for her. I have a program guide and I looked for fun things and I taped pro-
grams I thought would interest her and I gave her some poems I had writ-
ten. And she didn’t get on her high horse and say: “I can’t accept this.” She
let me become attached to her without making a big deal about it. She
handled it very nicely. At the same time she made it clear that she couldn’t
return the favor. So she was open to it and accepting and happy about our
relationship. I felt as though I could give and receive the trust that I felt for
her without her rejecting me. The one that was there before her was more
reserved. I was very attached to her, too, but we never bonded in the same
way or got close because she was very reserved. She had that barrier
against getting too involved, to put it that way. The one I had after that
was totally different. So it was much easier with her. It was accepted that
I was attached to her. The first one was so afraid that I’d get too attached.
But the last one accepted it, and I could be myself. She accepted the tapes
and listened to them and then I got them back and played them again. I lent
her books I thought she’d like.

Kari contrasts the two nurses with one another. The first one
maintained a distance between them by raising a barrier between
herself, a staff member employed to help the person, and Kari, a
person in need of support and treatment. Personal ties within such
a framework are thought to harm the person and diminish the pro-
fessional’s ability to determine the person’s needs and to help her in
an adequate way. The nurse she had afterwards behaved differ-
ently; she did something different by accepting Kari’s small gifts.
This reciprocity was truly meaningful for Kari. As she explained,
having a relationship with a clinician or profession that extends
beyond the standard user-caregiver relationship was important to feeling cared about and supported. The contrast she drew between those professionals who maintained strict boundaries and rules about interacting with patients and those who did not was reinforced by other informants. For example, Erik described several important interactions with a nurse, Vera, who worked at an activity center run cooperatively by psychiatry and the social services:

After I had worked there for a month she came and gave me a rose. It’s dried up now and I have it at home. Small things like that. Or like last month when I was trying to scrounge up a little food and she lent me 100 crowns because I didn’t have any money left at the end of the month. She got it back today. She calls me at home and asks about me. She calls my mother and tells her how things are working out for me at the job. It’s really calmed my mother down a lot. She says she’s so happy that I’m healthy now. I’ve explained to her that I still see things around me, but that I don’t pay any attention to them. That’s what feels so good, that even my mum has accepted it.

In the majority of the interviews, episodes are described where professionals did not do what was expected of them. As an example of doing more, Vera called Erik’s mother with encouraging words about him. But in extending her relationship with Erik beyond the traditional role of caregiver, Vera’s actions represented doing something differently; this is what made Erik pay notice. That a mental health worker gives a person a rose to celebrate his progress does not fall within the institution’s rules and expectations. If handing out roses were a rule, it would probably not have had the same effect on Erik. The rose was a personal gift from Vera to Erik. Vera did something different from what was expected of her. She also did something different when she lent Erik money out of her own pocket and called him at home without having a special reason to be worried about his condition. Her actions seem to have been generated by a personal concern for Erik’s well-being. Vera does not loan money to just anyone, just as she does not make a phone call to just anyone’s home; Erik has been chosen.

Another aspect of what we are describing here is when the professional negotiates with the person about which interventions should be made and in what ways. In several of the stories, the person accepts the professional’s suggestion, but shares the responsibility with him or her. Jan described how he dealt with situations
when he started to feel worse. One of the things he did was to change the dose for his medication:

Interviewer: So you avoid the situation, you sleep and increase your medication?
Jan: Yes, that’s right. That’s also what my doctor said; OK, we’ll go with a low dose now, but if things start to get critical you’ll have to take an extra tablet on your own. That sounds reasonable to me and so it’s what I’ve done. During those periods when I’m feeling better I space out the intervals, like take a pill every other day or so. I adjust the dose myself.

Jan regarded his doctor’s suggestion as “reasonable” and thereby something he could use, but the decision to change medication was something that was negotiated between doctor and patient. Kari described a similar experience:

Interviewer: And what about the doctor? What would you say was the special thing about your relationship with him?
Kari: That he allows me to decide a little for myself.
Interviewer: Like?
Kari: Like, for example, he didn’t make a fuss when I only took the medication every other night.
Interviewer: You were supposed to take it every night?
Kari: Yes. And when I didn’t take the sleeping pills, he didn’t say anything. He let me sleep every other night.

When a doctor delegates some of his or her power to a person who has been diagnosed with a severe mental illness, it indicates that the doctor does not equate the person with the diagnosis. This can be experienced as showing confidence in the person’s own judgment, and acknowledging the person’s ability to make reasonable decisions. Kari explains how she and her psychiatrist decided, for example, what to talk about:

Interviewer: Do you have any other examples that describe the kind of contact you had with your psychiatrist?
Kari: I think he’s calm and balanced and listens to me and what I have to say and doesn’t have a whole program he has to follow. I can talk about everyday stuff that’s important to me. It doesn’t have to be about all kinds of problems...So I decide what to talk about. He hasn’t set any agenda or program that we have to follow. And he is so wonderfully calm.
Like Kari, Mia describes the importance of making her voice heard and her wishes known: "The night team was wonderful. At first they told me I should go to the hospital, but I said I just wanted to talk. And that’s what we did; we talked sometimes about problems, sometimes just about things in general." The people on the night team who visited Mia at home agreed to forego their own suggestion and followed hers. By doing so they confirmed her identity and status as a citizen possessing civil rights, even though she has been diagnosed with a severe mental illness.

Kari and Mia both emphasized how important it was that in their sessions with helping professionals they could talk, not only about problems, but also about small things, like events from everyday life. It may be that it is having a normal conversation within the context of an artificial relationship that is what makes this factor so effective. And perhaps what is the most important aspect here is not the normality of the topic of conversation, but that this normality takes place in a clinical setting in which it would normally be considered out of place. The important thing is not simply to talk about everyday matters. Nor is the important thing to meet with an expert. Rather, what is important is meeting with an expert to talk about one’s problems and to talk about other commonplace matters as well.

What is the Difference?
In all of the narratives, informants talk about clinicians doing something different than would normally be expected; either in spending more time with them, choosing them as special, or perhaps breaking rules for them. Investigating what characterizes this different way can help us to define more precisely what in the professional’s actions people have found to aid their recovery.

Professionals who "do more" or "act differently" take a risk. They are breaking the rules of the institution and thereby risk being criticized in the performance of their professional role; they can be accused of being overly involved. When a professional does something different, he or she emerges as a real person. The relationship with the person ceases to be a neutral one. To be chosen by a member of staff means that the professional has chosen just you, usually on the basis of personal criteria. The relationship becomes emotionally charged. Although one could argue that many professionals do more, do something different, and do something in a different way (cf., e.g., Bauer, 1997; Frank, 1974; Gardiner, 1971; Lambert & Dupper, 2003; Roazen, 1995), their actions are seldom discussed
in the public arena. This puts them at the mercy of the patient; he or
she could expose them. The formal and unequal power relationship
is balanced by mutual trust and dependence. The extent to which
this reciprocity has developed varies in the narratives. Mia gave
an example in which she and her nurse had developed their knowl-
edge of one another by sharing common experiences:

I asked him if I could have his phone number and if he wanted to be my
contact person. He thought I meant there at the hospital and so he said
yes, but later I asked if we could keep on. I didn’t know how he would
get paid, but it’s worked out for 11 years. The community pays him. We
go to each other’s homes. Or else we go out and have a meal together, or
go to the movies or listen to music. It’s wonderful. We like the same music,
or at least I’ve begun to like his kind of music. Or we go sledding. That was
a lot of fun. We’re like a family and I get to have a mom-dad-baby family,
although it’s not my real parent.

As described by the people we interviewed, the professionals’
contribution to recovery from severe mental illness often consists
of quite commonplace actions, which often defy expectations of
both “mental patients” and the professionals who treat them.
Rather than strict adherence to guidelines and professional expecta-
tions, Kari says that it was precisely because her doctor lacked a
predetermined plan of treatment that he was able to contribute to her
recovery. “He has no set agenda or program that I have to follow.”
She described the nurse who helped her as being “totally different”
from other nurses she had met: “She was open to [the tapes Kari gave
her] and accepting and happy about our relationship.”

Contrary to the fears of many professionals, the people who were
interviewed quite easily distinguished help from professionals
from that of friends or other loved ones. Mia referred to her
relationship to her contact person and his family as a family
relationship. At the same time, she was well aware that they were
not her real family. When Kari described her relationship to a pro-
fessional who had helped her, she used a term that often occurs in
interviews with people who have recovered: “as-if” friends (“like
friends”). To be “like friends” refers to that “something different”
we discussed earlier. As we have seen in the interviews, there are
professionals who “do something different,” and this something
different is connected with having a “like-friends” relationship
with the person. “Like-friends” relationships seem to occur in a
variety of settings in different countries and in different cultures.
The rules that are broken are among those that are considered prerequisites for the traditional institution’s survival. It is quite likely that most professionals vacillate from case to case between the different forms of “professionalism.”

However, although this new kind of professionalism seems to be beneficial and not at all uncommon, it is seldom accorded the same value as a more formal sense of professionalism. Rather, the tendency is to suppress knowledge of it and to characterize it in official contexts as unprofessional and evidence of “overinvolvement” or “failure to maintain distance.” In this sense, the “like-friend” relationship constitutes breaking the rules and professionals who do so take a risk. Not only have they broken the rules of the institution where they work, but they have also called into question institutionalized knowledge about madness.

DISCUSSION

The personal experiences we have related in this study clearly indicate that social interaction is of importance to the recovery process, whether that interaction is with family and friends or clinicians and other professionals. Throughout the narratives, informants talked about the importance of having support while they learned to cope with their illnesses. They talked about people in their lives knowing them as full people and having patience with them and also having confidence in them to make good choices. These actions occurred in the everyday choices and activities of people with mental illness: spending money, taking medication, and spending time. What then are the similarities and the differences between what people in the person’s social network do and what professionals do that can contribute to the recovery process?

Family members have a shared history, and are often part of the same social network, as the person in recovery. In our society, people who are close to one another are expected to help and stand by one another. Thus, everyday life is the family’s arena, with the kind of help family members providing usually connected with the activities of daily life (see Breier & Strauss, 1984; Denhov, 2003). In many cases, families bear a heavy burden when one of them develops a mental illness. A brother or sister might anxiously wonder why his or her sibling became ill. Parents might be tormented by thoughts of what they may have done wrong during the
child’s early years. The picture is complicated by feelings of guilt, shame, and anger. Families who continue to stand by a member who is ill risk becoming just as socially isolated as their loved one. They are forced to bear a greater share of the burden when others turn away. It might begin by other people remarking that the family has become too involved and is actually harming the one they are trying to help.

Professional helpers, on the other hand, meet with patients because they are paid to do so, and it is usually only for a limited period of time. They meet many such people every working day and are seldom in a position to follow up their patient’s development for a long period of time. The kind of help professionals provide is determined by their education and training, and by their supervisors. For professionals to remain with a person through the course of his or her illness, or to do more than what is expected, may entail changing how professionals work in institutions, how they view their work, and how they are viewed by society.

Relationships—with friends, family, or professionals—have a major impact on whether a person feels demoralized and isolated, or, conversely, confident and whole (Davidson, 2003; Frank, 1974). To stand by someone, to remain by his or her side, and to become involved over and above familial or professional duty is what appears to makes the difference between help and hindrance. As we have seen in these narratives, an intervention does not acquire meaning simply through the official position, or lack of official position, of the person performing it. It is the context that determines the meaning of the action, but it is the action that makes the difference.

REFERENCES


