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Communication Between People With Schizophrenia and Their Medical Professionals: A Participatory Research Project

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The authors describe a participatory research project undertaken by a group of people with schizophrenia under the guidance of a university researcher. Participatory research involves members of the research group in meaningful participation in all stages of the research process. In this study, group members chose the topic—experiences with medical professionals—and method of data collection—in-depth interviews that they conducted with each other. They developed and performed a readers' theater presentation of the results and their recommendations for how they would like to be treated by medical professionals. The results indicate that good communication with medical professionals is essential to people with schizophrenia; it helps them accept the fact that they are ill and learn to live with the illness. The research offered a transformative experience to group members and is contributing to change in the practice of health care for people with severe mental illnesses.

Keywords: *communication; doctors; mental health professionals; schizophrenia; participatory research*

A good relationship with health care practitioners is important for everyone who is ill, but it is particularly important for those who have a severe mental illness such as schizophrenia. Medications, although generally an essential part of treatment, are but one factor in helping people with schizophrenia to become well and to rebuild their lives. The therapeutic relationship between people with schizophrenia and their medical professionals is integral to the recovery process in schizophrenia and influences the outcome of the illness (Ivezic, Ljubimir, & Urlic, 2001).

AUTHORS' NOTE: All authors have agreed to be listed as such for this article.

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Good communication on the part of health care professionals is an essential element in developing the strong practitioner-patient relationship necessary in the treatment of schizophrenia (e.g., Burns et al., 1999; Eisen, Dickey, & Sederer, 2000). This relationship is not served if health care practitioners do not make an effort to understand the experiences and point of view of people with schizophrenia and exclude them from participation in decision making about their treatment. For example, the willingness of health care professionals to provide information about the illness and about medications and to answer patients' questions has been shown to be crucial for developing and maintaining an effective therapeutic relationship (e.g., Hornung, Klingberg, Feldmann, Schonauer, & Schulze Monking, 1998; Llewellyn-Jones, Jones, & Donnelly, 2001; Oehl, Hummer, & Fleischhacker, 2000). Despite this research, a significant number of doctors do not even tell patients when they are first diagnosed that they have schizophrenia (Clafferty, McCabe, & Brown, 2001) and thereby create a conspiracy of silence around the illness. Doctors also might prescribe medications without understanding and acknowledging the degree of patients' distress about the often severe side effects. Such actions damage the therapeutic relationship and thereby contribute to the continuing illness rather than recovery of people with schizophrenia (Day, Kinderman, & Bentall, 1998).

In this article, we contribute to this literature on communication between health care practitioners and people with severe mental illnesses with a report of a participatory research project in which we explored the role of communication with medical professionals in the lives of 11 people with schizophrenia. The research project was conducted in Calgary, Alberta, Canada, between October 2001 and October 2002 by members of the *Unsung Heroes Peer Support Group* for people with schizophrenia in Calgary, all of whom have schizophrenia, guided by Dr. Barbara Schneider, a researcher from the University of Calgary.

Schizophrenia is a complex biochemical brain disorder that is estimated to affect about 1% of the population. It occurs in normal, intelligent people in all walks of life and affects perception, thinking, feeling, and behavior. Its symptoms include, among others, hallucinations, delusions, and disordered thoughts. A new generation of medications has relieved some symptoms of the illness and improved quality of life for a significant number of people, but about one third of people with schizophrenia do not respond well to medications (Torrey, 2001). These people try many medications over a period of years, searching for one that works for them. About 10% of people with schizophrenia commit suicide (Torrey, 2001). Schizophrenia also causes cognitive damage that remains after the psychotic symptoms have abated, often making it difficult for people to carry out even the normal tasks of everyday living, to say nothing of paid employment. A particularly tragic aspect of schizophrenia is the isolation it produces in its sufferers. It "causes people to feel disconnected from themselves, from others, from their environments, and from meaning and purpose in life" (Manitoba Schizophrenia Society, 2000, p. 8).

The participatory approach taken in this project not only had the potential to contribute to an understanding of the experiences of people with schizophrenia but also offered the people involved an opportunity to overcome the isolation so characteristic of schizophrenia by connecting with others in the same situation to research a topic of importance to them. Group members chose the topic—experiences with medical professionals—and the method of data collection—in-depth interviews that they conducted with each other. A research assistant, who is cited here as a coauthor, helped to analyze the interview transcripts. Group members produced a

set of recommendations for how they would like to be treated by their medical professionals. Results of the research were disseminated to the public in the form of a readers' theater presentation developed and performed by group members. The main conclusion of this participatory research project is that good communication with medical professionals is essential in the lives of people with schizophrenia. Getting information about diagnosis, medication, and available support, and being treated with dignity and respect helps people with schizophrenia to accept the fact that they are ill, come to terms with having schizophrenia, and learn to live with the illness.

We begin with a discussion of the tenets of participatory research and review the literature on the use of participatory methods with people who have disabilities. We then describe our approach to the research and our experience of carrying it out. This is followed by the results of our research, including a set of recommendations generated by group members for how they would like to be treated by their medical professionals. We close with a discussion of the benefits of this project in generating knowledge about the experiences of people with schizophrenia, in offering a transformative experience for the people involved, and in contributing to change in how people with schizophrenia are treated by their medical professionals.

PARTICIPATORY RESEARCH

This research project is embedded in a tradition of cooperative inquiry that emphasizes working with community groups as co-researchers (e.g., Fals-Borda & Rahman, 1991; Reason, 1994). This approach stands in stark contrast to the traditional scientific approach to knowledge generation, which places the academic researcher at a distance from the subjects of the research to produce "objective" knowledge. The participatory approach assumes that the experts are the people who live the experiences that are being studied, and that knowledge is something that is produced through the active engagement and interaction of all members of the research group. Participatory research thus strives to transform the social relations of research (Oliver, 1992; Zarb, 1992) by regarding participants as both co-researchers and co-subjects. In particular, participatory research involves the members of the research group in meaningful participation in all stages of the research process, including developing the research question, gathering the data, analyzing the data, and disseminating and using the results. Ideally, the research not only produces knowledge but also is transformative in some way for the participants.

Participatory research has emerged as an important and legitimate method of conducting research with people with disabilities. It is valued for what it can contribute to an understanding of the experiences of and the issues faced by people with disabilities (e.g., Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1999). It is often described as having an emancipatory or empowerment agenda, particularly as a tool for improving the lives of people with disabilities (e.g., Balcazar et al., 1999). Participatory methods have been used with people with physical disabilities, for example, Stewart and Bhangwanjee's (1999) study of people with spinal cord injuries; Campbell, Copeland, and Tate's (1998) Project Inter-Seed, which examined the health care experiences of people with physical disabilities; and Krogh's (2001) study of home support services for people with physical disabilities and chronic

illnesses. It has also been used with people with learning difficulties. Richardson (2000), for example, worked with 6 people with learning disabilities over a period of 18 months, researching their lived experience.

Participatory methods have also been used in research with people with schizophrenia. The Bridge to Discharge Project (Canadian Nurses Association, 1996) was a participatory research project that resulted in a program designed to help people with schizophrenia to integrate successfully back into the community after long-term hospitalization. Davidson, Stayner, Lambert, Smith, and Sledge (2001) used a participatory approach to involve 12 people with schizophrenia in exploring reasons for relapse and designing a program to help them successfully avoid relapse. They note that conventional approaches to research "provide yet one more source of the loss of self, unwittingly undermining rather than promoting recovery by treating the person with the disorder as a passive object to be investigated and acted upon by others" (p. 163).

There is much debate over various aspects of participatory research as a method for carrying out research with people with disabilities, particularly in regard to the role of the academic researcher, who is often not disabled (e.g., Chappell, 2000), and to the question of whether participatory research can be truly emancipatory (e.g., Chappell, 2000; Richardson, 1997). However, it is not our purpose in this article to explore these issues. Rather, we describe our research here to disseminate the conclusions and recommendations arising from the research and to show the value of participatory research with people with schizophrenia.

METHOD

Reason (1994) has described four phases in participatory research. In Phase 1, the researchers agree on an area for inquiry and generate some initial research propositions. They also agree on a set of procedures by which they will observe and record their own and others' experiences (i.e., gather the data). In Phase 2, they begin to initiate the agreed action and to observe and record their own and others' experiences. In Phase 3, they become fully immersed in the doing of the research. Reason (1994) described this stage of full immersion as fundamental, the stage at which the transformative potential of participatory research begins to be realized. In Phase 4, the researchers revisit and revise their original research propositions, analyze the data, draw out results and conclusions, and prepare to present their research publicly. We will use this four-phase framework to describe the research experiences of our group.

Phase 1. The project was initiated by Dr. Barbara Schneider in response to a call for grant proposals for participatory research projects from the Canadian Centre on Disability Studies. Dr. Schneider approached the Schizophrenia Society of Alberta, Calgary Chapter, and after consultation with members of the Unsung Heroes support group for people with schizophrenia run by the Schizophrenia Society, she and the woman who runs the group (who has schizophrenia) submitted a proposal for the participatory project described here. The grant proposal was successful, and ethics approval for the research was obtained from the University of Calgary Research Ethics Board. Members of the research group, which consisted of some of

the members of the *Unsung Heroes* support group, were not offered confidentiality or anonymity, as it was the intention from the beginning of the project that participants who wanted to would take part in the dissemination of the research. However, as no names are associated with the quotations from the interviews that appear in the readers' theater presentation or in this article, we have preserved the anonymity of those people who were interviewed but did not take part in dissemination. All members of the research group signed consent forms, and when others were interviewed, they also signed consent forms.

The research group began meeting in October 2001. Meetings took place twice a month for an hour before the regular *Unsung Heroes* meetings. Attendance was variable throughout the course of the research, but a core group of about seven members became engaged in the research and participated throughout the project. We began by brainstorming a number of topics and settled on one that was of interest to everyone: experiences with medical professionals. We considered a number of methods for exploring this topic and decided to conduct in-depth interviews among the members of the group. After settling on a topic, we constructed a list of interview questions. We brainstormed questions, with each member contributing questions that he or she thought were relevant to the research topic. The questions were organized into groups of related questions, and the group then went over the list, revising, adding, or deleting as seemed appropriate. After the questions were finalized, a copy was printed for each member of the group.

Phase 2. Interviews began in January 2002. All interviews took place in the group setting. We sat around the table in the Schizophrenia Society office meeting room while one member of the group interviewed another member. The rest of us listened and occasionally contributed comments or asked follow-up questions. With the exception of the university researcher, none of the members of the group had ever conducted interviews, and most had never been interviewed. At first, everyone was quite nervous about the interviewing, questioning their ability both to conduct interviews and to be interviewed. In addition, there was some anxiety about the tape-recorder being used to record the interviews, but, as with every stage of the research process, the group members learned by doing. After discussion, led by the university researcher, of what was entailed in interviewing, two brave members offered to be the first to interview and be interviewed. This was followed by group discussion of what was good about the interview and how the next pair might improve on what had been done. As the interviews proceeded, all members of the group took part, as interviewers, interviewees, or both, and their confidence in their ability to participate in the process increased. We also conducted interviews with several people who attend *Unsung Heroes* meetings sporadically and came to the research group meeting only to be interviewed.

Phase 3. The group became fully engaged in the research process. Everyone became very comfortable with the experience of interviewing. We fell into a pattern of conducting two interviews at each meeting, each about half an hour long. We became much more comfortable following lines of questioning, rather than sticking to the list, and those of us who were listening to the interview felt free to jump into the interview if we heard something we wanted to follow up on. We conducted the final interviews as group interviews: One person agreed to be interviewed, but no

one was designated as the interviewer, and anyone who wanted to ask questions did so.

As the interviews progressed, we realized that we had created a place in which members could talk freely about aspects of their lives that they normally have no opportunity to talk about. The *Unsung Heroes* support group provides a supportive environment for talking about current problems in coping but not for sharing past life experience. Hearing details of the life experiences of group members was often an emotional experience, both for those who were describing their experiences and for those who were listening. The structure of the interview process allowed even people who rarely speak at *Unsung Heroes* meetings to tell their stories. Through the interviewing, we became a caring and supportive community of friends.

Phase 4. The interviews concluded in April 2002, and in May, we began data analysis. We had 11 interview transcripts and one transcript of a meeting at which we had talked generally about our experiences with medical professionals before beginning the interviews. These transcripts were made from the tape-recordings by a professional transcriber. The group members, without any input from the academic researcher, decided to conduct a thematic analysis of the data, although they did not call it that. Based on the experience of listening to the interviews, they had a strong intuitive sense that they wanted to compare stories on a number of topics that everyone seemed to have mentioned. These included such topics as medications, experiences with doctors and nurses, and good and bad experiences in hospitals. The group members generated a list of categories and assigned a color to each category. We then began reading the transcripts and marking sections with the appropriate colors.

The group members had great difficulty with this part of the research process. Because of the cognitive difficulties associated with schizophrenia, some group members have limited ability to concentrate for long periods, and many have difficulty reading and writing. After two meetings, at which we made almost no progress in coding the transcripts, a graduate student in communications studies from the University of Calgary was hired as a research assistant to assist with the data analysis. She used the categories that group members had created, added the central category of communication in which all the others were embedded, and proposed an analytic scheme that incorporated all of the categories. This scheme was then presented to the group members for discussion and, after some modifications, was used to organize the results that are presented below.

In keeping with the principles of participatory research, it was our intention from the beginning of the project that members of the research group would take part in the dissemination of the results. The next step in this phase of the research was, therefore, the construction of a script for a readers' theater presentation to be performed by group members. The script was written by the university researcher based on group suggestions about content and includes quotations from the interviews selected by group members. The group's very powerful and moving presentation has, at this writing, been performed seven times and been seen by several hundred health care professionals. To achieve wider dissemination of the project through academic publication, the university researcher asked permission from the members of the group to write an academic article and to include them as coauthors.

This article was, therefore, written by Dr. Schneider, lead researcher, drawing on academic literature in the field, material generated in the research, and discussions among the participants. However, as the principles of participatory research remind us, true participation belongs to those who take part, not those who write about them.

RESULTS

Most of the participants in the *Unsung Heroes* group tell similar narratives of their experiences with medical professionals. Central to almost all of their experiences is the issue of communication. We use the word *communication* in two senses: communication to transfer information and communication to build relationships. Our results are organized around four main interrelated themes of diagnosis, medication, information and support, and treatment, all of which are embedded in a central issue of communication. When the people who were interviewed were not told their diagnosis, were not given adequate information about medications and their side effects, were not informed about schizophrenia and the available supports, and were not treated with dignity and respect, they generally had bad experiences with medical professionals and stayed in a state of denial about having schizophrenia. When information was more successfully communicated to them, when the diagnosis was clear, the medications explained, support made available, and they were treated as persons deserving dignity and respect, they generally had more positive experiences with medical professionals and began to accept having to live with schizophrenia.

Although participants describe many negative experiences with medical professionals, our research is offered not so much to be critical as to increase understanding of the experiences of people with schizophrenia. We do not, of course, speak for all people with schizophrenia, only for the people who were interviewed for this project. What follows represents the words and experiences of the members of this research group.

Diagnosis

Diagnosis can be problematic in mental illness, and it is often very hard for medical practitioners to come to a definitive diagnosis. This, in turn, puts people with schizophrenia in a difficult position. When doctors are reluctant to commit themselves to a specific diagnosis, when the diagnosis takes years or changes frequently, or when people are simply not told anything specific, it is extremely distressing for them. This lack of clear communication about their illness is very frustrating and makes it much harder for people deal with their situation. One woman put it like this:

For cancer or heart attacks or anything they always tell you, "You've had a heart attack, you've got cancer, you've got leukemia." Only with mental illnesses they won't tell us.

She described receiving conflicting diagnoses from her doctors:

When I first went to the hospital, my doctor did not tell me. The practicing student doctor took me aside, and he says, "We think you have paranoid schizophrenia." But my doctor would not tell me. He did not give me the diagnosis.

A number of the participants talked about a specific point in their medical history when their diagnosis became clear to them. Before that point, however, they remember mainly confusion, conflicting diagnoses, and frustrating experiences with their doctors. Many participants could talk about their diagnosis only by referencing the long period when they and their doctors did not know what was wrong. One participant noted that it took almost 14 years for doctors to put a diagnosis with his disorder. One of the participants still has not received a clear diagnosis from her doctors. She feels that knowing her diagnosis is essential to be able to deal with being mentally ill. Many have had a number of doctors over the years, each giving a different diagnosis. One participant told of his frustration with a change in his diagnosis on the very day of the interview for this project, saying,

I was told today that my diagnosis with schizophrenia seven years ago may be flawed. I feel like I'm living a big lie. I'm fed up with it and I wish that some big fool would make up their mind.

Without a clear diagnosis, participants could not begin to deal with having schizophrenia. Even with a clear diagnosis, being labeled is in itself problematic. As one man said, "You have to be labeled, and that was the hardest thing. It was like, 'Oh man, this is all I need.' "

Medications

In addition to lack of communication from medical professionals about diagnosis, there was also lack of communication about the medications used for treatment. Potent medications, and their sometimes very debilitating side effects, including weight gain, lethargy, vision problems, elevated blood sugar, increased risk of diabetes, constipation, dizziness, loss of sexual drive, headaches, and hair loss, are a central reality in the lives of people with schizophrenia. The participants talked often and at length about their experiences with different medications. The trade-off that is clear for medical professionals—that it is better to take the medication to reduce psychotic symptoms and put up with severe side effects—is not at all so clear to those who have to take the medications.

Many found it difficult to deal with the unwillingness of their doctors to discuss treatment options with them. They also complained not only about the debilitating side effects of the medications but also about not being informed about possible side effects and not being able to communicate their experiences and concerns about medications. As one man said, "They don't tell you about the side effects, and the side effects are just incredible." One woman described how the medications were presented to her:

They just said "You have to take your choice; you either take the meds and take the repercussions, which are the side effects, or you go around being insane. So what do you want to do? You have to pick." Do I want to walk around crazy, or do I take

weight gain and stiffness and blurred vision and dry mouth and all the other things . . . ? They just kind of forced it and said you have to take this. There was just no argument with them. They were saying this works.

Many described being overmedicated at various stages of their illness, some saying that they mistook the side effects of the medication for the symptoms of the illness. One participant talked about a time when the side effects were so bad that he decided to go off his medications. As one woman said, "It is really hard to explain to them how it feels when they give us too much, but it is like being tied up in certain areas of us." Another man's description of being on medication struck a particular chord among the research group members:

I feel weighted down by the medication. It's hard to move, walk, do things. It's like walking in slavery, like lifting heavy bricks all the time, weighed down by the illness.

One participant said he was not told about possible changes in his mental state when he changed from one medication to another.

I'm really going to give it to [my doctor] with both barrels, because I changed over to Olazapine [a medication] and he didn't tell me it would take two weeks to kick in properly.

Another recounted her doctor's dismissal of her concern about the weight gain caused by her medication:

I was concerned about my weight gain . . . and I'm bringing up this concern, and he says, "Well don't you feel more voluptuous? Don't you notice men noticing you more?" And I'm like "What?" I said, "What is wrong with you?" I said, "I don't feel that way. Actually I feel less attractive and I don't feel healthy."

Information and Support

Receiving information about schizophrenia and about where they can get support is essential for people to be able to deal with having schizophrenia. Even when the diagnosis is definite, there is no guarantee that it will actually be "clear" to the person. One man said he had little comprehension of what schizophrenia was when he was first told he had it, and as a result he experienced fear and apprehension. Many participants described themselves as being in denial, especially when they were first diagnosed, and said that they were not told that they were ill or given any information that would help them overcome the denial. This denial, which is actually a lack of awareness that one is ill, is a hallmark of schizophrenia and makes it hard for people to take in information about the illness. Nevertheless, participants felt that it would have been helpful to have been told, for example, that what they were experiencing were delusions. Participants rarely recalled their doctors as being helpful to them in understanding their illness, saying they got more information from nurses and support groups, such as the Schizophrenia Society. Some participants had to seek out information on their own from places such as the Internet and television advertisements. Participants emphasized that they also want their doctors to communicate with family and friends and to provide them with information about

schizophrenia. If family members do not understand the illness, it is difficult, if not impossible, for them to be sources of support.

In spite of now having information about schizophrenia, one participant noted that in some ways, he is still in denial:

I still have a hard time dealing with the fact that, yes, I have this condition. I'm still in denial and I probably always will be, because who wants to be this way?

Treatment

Many of the participants had very painful stories to tell about their past treatment, when they were not listened to or when they were not treated with respect and dignity, both in institutions and by their doctors.

Institutions

Most of the participants had been hospitalized at one time or another in various kinds of psychiatric institutions. Although some of them found their time there helpful, others had some of their worst experiences. There were many stories about how they were ignored, treated harshly, looked down on, and, sometimes, regarded as "less than human." They also talked about how they were made to feel like criminals when they were hospitalized, treated as though it was their fault that they were sick. As one participant put it,

I felt criminalized in the [hospital]. They took away my clothes and my privileges. You get treated like a criminal. But it's not my fault. It's the illness. They gave me a shot and put me in a side room, when I thought they were the mafia. They were very rough. It really hurt. I told the psychiatrist, but he got mad and yelled at me. They left me overnight, with no mattress, just a pillow and a blanket. They don't care how much torture it is.

In addition to being made to feel criminalized, they were also often ignored by the very doctors and nurses who were supposed to help them.

You go up to the nurses' desk and they all ignore you. They don't talk to you, they put their heads down and continue to do whatever. They don't even look at you or acknowledge you. It's like you're the invisible man on that soap commercial. And that's how they treat you. We're human. They think we don't hear, they think we don't process, but we're aware when we're being treated inhumanely.

Doctors

Participants felt varying levels of resentment toward their doctors because of lack of communication. They want to be treated with respect, and that means that they want medical professionals not only to supply information but also to listen and respond to their concerns. One man described his frustration in communicating his concerns to his doctors:

My doctors are making me feel like it's a brick wall, and I want to strangle my doctor but I can't, it's against the law. . . . And until I change doctors I guess I feel like a

guinea pig and it's like hitting brick walls. It's very frustrating and I'm tired of feeling that way. I just want to be heard, I guess, about the subject.

One person talked about how some doctors adopt a superior stance—"They think they're gods and that what they say is gospel"—and are not willing to take time to answer questions. Another told a story about his new psychiatrist cleaning his nails during his appointments rather than attending to what he was saying. Another asked to be treated as a whole person rather than as someone whose mental functioning is the only concern. One participant asked to be heard by all her medical practitioners, saying, "I want them to listen a hell of a lot better than they do."

Positive Experiences With Medical Professionals

When participants did not feel that their medical professionals were communicating well with them, they recalled negative experiences. On the other hand, when the medical professionals around them made an effort to develop good relationships with them, the participants recalled much more positive experiences. Rather than dividing these experiences into our four main themes, we present these in one group. Good communication, in both the informational and the relational senses, is central to these experiences. Good communication brings our four themes of diagnosis, medication, support, and treatment together in the lives of people with schizophrenia. When people get a definitive diagnosis, get information about medications, get the information about the illness and the support they need, and are treated with dignity and respect, they begin to feel much more accepting of their situation. They start to understand the need to take their medications and to look after themselves, and they start to see ways to deal with their situation. Good communication enables them to move from denial to acceptance, to adapt their lives to the illness, and to cope with their difficulties.

Many participants described doctors who have helped them to get well and stay that way, and many are currently seeing doctors that they feel they have a good rapport with. Their doctors, unlike ones they might have had in the past, listen to their problems and respond to them. Some of the participants referred to their doctors and other mental health professionals as their friends, "professional" friends who help them accept and deal with having schizophrenia. They appreciate being involved with people who will listen to their concerns and genuinely attempt to respond to them. One woman, who was hospitalized during the time the research was taking place, returned to the group and described how different this experience was from her previous hospitalizations. She said that this time, she had a doctor who explained why he was changing her medication and thanked her for making the effort to understand why he was doing so.

Some of the participants recognize that it is important not only for the doctors to develop a relationship with them but also for them to communicate well with their doctors. As one man said,

You've got to have the right attitude, though, when you're talking to [medical people]. Because they have feelings too, just like anybody else, and they want to see that the person they're talking to is understanding them.

Many also feel that they must contribute to their own treatment. One man, looking back over his treatment, said that having his diagnosis disclosed to him by his doctors and getting information from nurses and others to help him understand the illness was important in his being able to become mentally well, but just as important was admitting to himself that he had schizophrenia and assuming responsibility for looking after himself. One man spoke about how he believed that his doctors could help him only if he was willing to help himself:

The psychiatrist is only as good as your own improvement . . . I feel I have to make a contribution, I have to work on my problems. [My doctor] allowed me to have my problems, to solve my problems. He helped to enhance my quality of life as a result. He made the good things better and he helped me to understand the bad things.

One woman also talked about her responsibility to participate in her treatment, saying that she feels the most important thing she has learned is that it is her responsibility to know about her illness and to take control of her own treatment. However, she pointed out that this can happen only if medical professionals are willing to listen to people with schizophrenia:

We [doctors and patients] need to have a working relationship where we both are respected for our opinions. . . . Before it was just one-way communication, now it's starting to be two-way.

Participants know that with the help of their medical professionals and support systems, they have done better than many people with schizophrenia in keeping themselves well and off the streets. As one participant noted,

You know we're all, everyone sitting here, is a success story, 'cause for every one of us here, there's many, many people that are not doing well. We have the best life and everything available for us. We should just count our blessings, the state we're in. I mean living on the edge is nothing new, just look around the world.

DISCUSSION

If there is one clear message that emerges from the research, it is that good communication with medical professionals, in both the informational and relational senses, is essential in the lives of people with schizophrenia. Participants' early memories of being ill are suffused with confusion and frustration, unclear diagnoses, inadequate explanations of medications and their side effects, lack of information about schizophrenia, and inadequate support. Getting information about diagnosis, medication, and available support helps people with schizophrenia to feel more positive about their experiences with medical professionals, and is essential in coming to terms with having schizophrenia and learning to live with the illness.

The feelings of participants about their experiences with medical professionals are also closely tied to how they are treated, both in and out of institutions, especially whether their concerns are heard and addressed. People with schizophrenia want to be treated by medical professionals as human beings deserving of the same dignity and respect as people with other kinds of illness. They are well aware that

their behavior while ill might make it difficult for medical professionals (and anyone else, for that matter) to regard them sympathetically and that being cooperative and having a "good attitude" makes it more likely that they will get good treatment from medical professionals. As one group member pointed out, however, it is hard to have a good attitude when you are ill, and medical professionals' memories of their behavior while ill can lead to them being treated without respect even after they start to get better.

The burden of establishing good communication must lie with medical professionals. When people are diagnosed with schizophrenia, they not only have no idea what is wrong with them, but they are also mentally ill and unable to manage their interactions with others. If a good relationship is to develop between medical professionals and people with schizophrenia, it requires a concerted effort by professionals to communicate with them, supplying the right information at the right times and being willing to listen. People with schizophrenia should not have to advocate for good communication and humane treatment. It is, instead, the responsibility of the professionals who are involved with them to understand their point of view, to communicate well with them, and to teach them and their families how to communicate well with all the medical professionals in their lives.

RECOMMENDATIONS

The members of the research group formulated the following recommendations for how they would like to be treated by medical professionals.

1. It is your responsibility as medical professionals to communicate well with us. We have schizophrenia. We are mentally ill and we can't always manage our interactions with other people. You must teach us how to communicate well with you.
2. Treat us with dignity and respect. No matter how sick and unstable we are, we are human beings. We are not a page out of the DSM. We should not have to have an advocate to be treated like human beings. We deserve the respect, dignity, kindness and normal treatment that other patients get.
3. Tell us what is wrong with us. If someone has a heart attack or cancer, you tell them what is wrong with them, but with mental illness, you often won't tell us. We deserve the same kind of information as other ill people.
4. When we come into hospital, don't take away our clothes and leave us naked in a tiny room. This humiliates us and makes us feel degraded and criminalized.
5. Let us rest when we are in hospital. We have had traumatic experiences, and our bodies are adjusting to large doses of tranquilizing medications. You let other patients rest. We need the same kind of rest to get better.
6. Don't send us out of town for treatment. This isolates us from our support network of family and friends, and does not help us to get better. Find a way to treat us close to home.
7. Listen to us and respond to our concerns about side effects, and about how medications affect our physical health. Our physical health is as important as our mental health.
8. Don't take power and control away from us. Empower us to be assertive and to make our own decisions. This will help us to adjust back into society. Give us the freedom to make our own choices.
9. When you treat us, think about how it feels to have schizophrenia, and how it feels to take large doses of medications. Remember these words: "It's like walking in slavery."

CONCLUSION

This research project makes contributions in a number of areas. First is in the production of knowledge about the experiences of people with schizophrenia with medical professionals. Although the literature acknowledges the importance of a good therapeutic relationship between people with severe mental illnesses and their medical professionals, we offer an understanding of this relationship from the point of view of people with schizophrenia. Our research foregrounds the consequences of poor communication in the experiences and lives of people with schizophrenia, and the importance of good communication with medical professionals as a key factor in helping them to live healthy and independent lives. The interviews provided an opportunity for group members to talk openly about very difficult matters in their lives, especially as they were talking to each other rather than to a "real" researcher. The data we gathered are truly a reflection of the experiences of these people with medical professionals.

Our research also illustrates the value of participatory research in offering a transformative experience to participants. Taking part in the research process, meeting every 2 weeks to interview each other and planning and performing in the presentations, made a tremendous contribution to the quality of life and sense of self of group members. Group members found increased social connection and support in the group, and meaning and purpose in the process of investigating what they regarded as an important topic. People with mental illnesses are a very marginalized group in society, and schizophrenia produces varying, but often significant, degrees of cognitive, social, and functional disability. The group members represented a range of abilities, some able to take active part in every stage of the research process and others able, for example, to be interviewed and participate in the presentation but not to take part in discussion. Two members had relapses and were hospitalized during the time the research was taking place and another struggled to attend performances because of symptoms. All participated to the degree that they were able and became valued members of the group, appreciated for their contribution and missed if they were not present. As one member said, the group "came together" in a way that made him proud to be a member.

There was also a real transformation in group members' sense of themselves as people who could accomplish something. They had all been subjects in many research projects and, at the beginning of the project, could not conceive of themselves as people who could do research. By the end of the project, they had taken on a sense of themselves as researchers. They saw that they could articulate problems, come up with ways to investigate the problems, and produce solutions. This experience increased their awareness of themselves as people with resources and strengths who could make a significant contribution to society. At a recent performance for psychiatry residents, when asked by an audience member what it was like for them to take part in the performance, one member said, "We feel like we really have a voice." Another expressed pride that "we have all become public speakers." Another said, "I feel really proud when people tell me what a good job I did. I feel like I am really doing something for the cause." The value of this project is reflected in group members' desire to do another research project, this time on housing for people with mental illnesses.

Finally, our research is also contributing to change in the practice of health care for people with severe mental illnesses through our influence on the psychiatrists and other professionals who see our performances. The response we get indicates that at least some of the doctors we speak to have not previously conceptualized the doctor-patient relationship in terms of communication. Our presentation offers them an understanding of the other side of the doctor-patient relationship and of the importance of communication in developing the therapeutic relationship. At one recent performance, a psychiatry resident raised his hand to tell us that as a result of hearing group members speak about their experiences at a previous performance, he has changed how he interacts with his patients. We could receive no stronger evidence that the goals of participatory research to empower people and improve their lives have been achieved in this project. This research project empowered one small group of very marginalized people with schizophrenia to speak directly to psychiatrists and other mental health professionals about their treatment experiences and through this is contributing to change in how others with mental illnesses are treated by their health care professionals.

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