Communication Between People with Schizophrenia and their Medical Professionals: The Script

This document presents a script that was put together by the members of the research group that participated in the research on communication with medical professionals. This script has been now performed in readers theatre format many times for groups of psychiatrists, psychiatry residents, psychiatric nurses and social workers. We have performed it at the Edmonton Schizophrenia Conference, the Foothills and Rockyview Hospitals in Calgary, and the Claresholm Treatment Centre. Members of the performing group take turns reading the sections of the script.

Introduction

In our presentation today we are going to describe a participatory research project undertaken by the members of the Unsung Heroes Support Group of the Schizophrenia Society, Calgary Chapter.

The research was funded by a grant from the Canadian Centre on Disability Studies.

Introduce speakers: Barbara Schneider, Hannah Scissons, Laurie Arney, George Benson, Jeff Derry, Ken Lucas, Michele Misurelli, Dana Nickerson, Mark Sunderland.

Present Outline of Presentation

Participatory Research

Participatory research is a form of cooperative inquiry that emphasizes working with community groups as co-researchers. All participants are seen as both co-researchers and co-subjects. It assumes that the experts are the people who live the experiences that are being studied. And it assumes that knowledge is something that is produced through the active engagement and interaction of members of the research group. Ideally, the research not only produces knowledge, but perhaps even more importantly, it also is transformative in some way for the participants.

4 phases of participatory research

Phase 1: The researchers agree on an area for inquiry and identify some initial research propositions. They also agree on a set of procedures for observing and recording their own and others’ experiences.

Phase 2: The researchers begin to initiate the agreed action and to observe and record their own and others’ behaviour.

Phase 3: The researchers become fully immersed in doing the research. This stage of full immersion is fundamental to the whole process.
Phase 4: The researchers revisit their original research propositions, analyze the material they have collected, and present the results to community and scholarly groups.

**Our project**

**Phase 1:** The research group began meeting in October, 2001. We met for an hour every two weeks right before the regular Unsung Heroes Support Group meetings. A core group of about 8 people came regularly. Other people came every now and then. We started by discussing the topic we wanted to research and settled on something everyone was interested in: *Experiences with medical professionals*.

We decided to conduct in-depth interviews among the members of the group and we constructed a list of questions for the interviews.

**Phase 2:** Interviews began in January, 2002. They all took place in the group setting. We sat around the table in the Schizophrenia Society office and one member of the group interviewed another member. The rest of us listened and occasionally made comments or asked follow-up questions. At first, we were quite nervous. We questioned our ability to do this. We were anxious about using the tape recorder. But as we went along, our confidence increased and we started to really like doing the interviews.

We also began to write journals about the research. Here are some excerpts from the journals.

*Laurie’s Journal, January 17, 2002.* I was asked to do an interview but I felt a little nervous. Maybe later I will. I do feel free to talk and make comments about topics and interviews.

*Dana’s Journal, February 7, 2002.* We are on our way. George and Mark interview very concise and to the point. Direct questions and to the point answers. Mark did very well in answering the question. He was very clear, and he had good insight into many aspects of the illness. It makes him feel weighted down, like walking in slavery. George asked questions on an even note, no highs or lows, and a nice friendly voice for questions.

**Phase 3:** We did two interviews at each meeting, each about half an hour long. We became much more comfortable, and we didn’t always stick to the list of questions. People would jump in if they heard something interesting that they wanted to ask about.

We realized that we could talk about things in our lives that we don’t normally talk about. Hearing details of other people’s life experiences was an emotional experience for everyone, especially when people talked about difficult periods in their lives. The interviews allowed people who don’t usually talk at Unsung Heroes meetings to tell their stories.
Laurie’s Journal, February 7, 2002. It was great listening to Mark. Usually he doesn’t say too much. He put into words what I think a lot of us feel when living with the illness. Knowing you are not alone is so important.

Laurie’s Journal, same day. I really feel different doing the interview. I was so interested in what Michelle was saying that I lost track of the questions I was asking.

Laurie’s Journal, February 21, 2002. I did another interview asking George questions. I found again it was interesting listening to answers. I tried to ask more in the same line, so he would explain more fully. What amazes me is most clients remember the medications they were on over the years, which can be a lot. It seems to me a lot of the medications have long difficult names and lots of side effects, and most remember what the side effects are.

Phase 4: The interviews finished in April, 2002. In May we began to analyze our data. We had 11 interviews, which were transcribed from the tapes by a professional transcriber. We decided to conduct a thematic analysis of the data. The group came up with some categories that we thought would be a good start. A colour was assigned to each category, and we began reading the transcripts and marking sections with the appropriate colours.

Laurie’s Journal, May 16, 2002. I read the transcript of my interview. I had trouble believing I talked like this. I realized a while ago that I have a communication problem, but I didn’t realize it was this bad. I think what I’m going to say, but when I go to speak, it doesn’t come out the same. A lot of the time I can’t pronounce the words or haven’t finished a sentence. I repeat words, and say words I didn’t mean to say. No wonder people have trouble understanding me and look at me with blank looks sometimes.

Michele’s Journal, same day. After reading my transcript, I realized we accomplished two things. We were able to vent our feelings and we were able to speak about many issues that affected us. And hopefully we will make a difference in making changes to our system.

Dana’s Journal, same day. I really don’t like trying to figure out what is good, bad, or indifferent about the things I have read in these papers. I prefer not to categorize it and let someone else do it. It’s hard to tell if my feelings for something would be the same as someone else’s. I would just like to get on with the writing of the presentation.

The group members hated doing the analysis. So at this point we hired a research assistant, Hannah Scissons, a graduate student in communications studies from the University of Calgary, to complete the data analysis. Hannah will tell you about this. She used the categories that the group members had chosen, added a few related categories, and produced the results that we present next.
Results

Before we go on to the results, we want to stress that we are not speaking for all people with schizophrenia, only for the people who were interviewed for this project. We also want to say that the group members know how complex schizophrenia is and how difficult it can be to deal with them when they are ill. We have some negative things to say about experiences with medical professionals, and we also have some positive things to say. Our research is offered not so much to be critical as in the hope that you can really understand the experiences of people with schizophrenia. These are the words and experiences of the members of this research group, and those of us who are lucky enough not to have schizophrenia must hear and honour those experiences.

In what follows, Hannah and I will provide a brief framework for the results, and the group members will read excerpts from the interviewees. They are not reading from their own interviews.

The main theme in almost all of the experiences with medical professionals is the issue of information and communication. We use the word communication in two senses: communication to transfer information, and communication to build relationships. When the people who were interviewed felt they were not informed about schizophrenia, including the diagnosis, medications, and support available, and when they were not treated with respect and dignity, they generally had bad experiences with medical professionals and stayed in a state of denial about having schizophrenia. When information was more successfully communicated, when the diagnosis was clear, the medications were explained, support made available, and they were treated well, people generally had more positive experiences with medical professionals and began to accept having to live with schizophrenia.

The results are organized around three main themes: diagnosis, medications, and treatment. In each of these themes, communication is the central issue.

Diagnosis

Diagnosis can be very problematic in mental illness, and it is often very difficult to come to a definitive diagnosis. This in turn puts people in a very difficult position. It is extremely distressing for them when doctors are reluctant to commit themselves to a specific diagnosis, when the diagnosis takes years to come to and changes frequently, or when they are simply not told anything specific. They are frustrated and it is much harder for them to deal with their situation.

* 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…. So he would tell me one thing, then I'd have a meeting with the resident, he'd tell me something else. And I'd go back and I'd tell my mom, "well the resident said this and the doctor said that." I guess they thought I was a good case to give to the resident.
* [I was diagnosed as having a condition in 1986]…but it was unclear until 1999 what my actual diagnosis was… It took them almost 14 years to actually put the diagnosis with my disorder.

* First it was schizophrenia, then manic depression, then hypo something, hypo activity or some type of thing. Then another one was that I had no adolescence. So they decided I became an adolescent because I left my parents when we got married. And then the last one was schizo-affective. So, it's like, what really does the diagnosis mean?

* 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 minds. My original psychiatrist that diagnosed me retired three or four years later. He told me I would have a better chance to go on AISH being diagnosed with schizophrenia than depression.

* You have to be labeled, and that was the hardest thing. It was like “Oh man, this is all I need.”

* But you know, 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.

Tied to the difficulty with diagnosis is the difficulty in getting information about schizophrenia. We want to acknowledge recent research that shows that when people are ill, it is very hard for them to take in and remember information. Nevertheless, this is how they remember their frustration getting information in the early stages of the illness, especially when they are in denial.

* When I was first diagnosed, I'd say, “I'm not like the rest of them, I'm not schizophrenic, I'm not like that.” But when you're sick with schizophrenia, you don't process the information. The resident came down really hard on me, and she wouldn't even deal with me after that. She'd never see me again. I couldn't see that I was really like all the other mental patients. They never told me that your thoughts could go off track, that when your brain goes off track, it affects brain processes and behaviours and things like that.

* I resisted like most people because I didn't understand the implications of everything that was happening. But from 1999 to present day 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?

* Nobody, nobody was telling me I was suffering from delusions. They had me thinking that I had developed a second personality, but I didn't. It was a delusion, it wasn't real. It was the idea that I had a second personality.
* When I first learned that I had schizophrenia, it was like "Okay, schizophrenia is that something from the dark ages? Is that a mid-evil illness? Am I going to be treated like they treated people in the mid-evil ages? Are there asylums in Canada like there are in the States, where I will be committed and never ever get out of?"

* I was totally ignorant [about schizophrenia]. I was. And then one day I was watching Channel 4, and there was a little blurb about volunteer places and stuff like that. And I saw this little ad for the Schizophrenia Society, and I’m going, “Oh, I never heard of that place.” I wrote down the phone number and I called.

* I found that I got more information from the Schizophrenia Society than I ever did from any doctor.

* One of occupational therapists handed me a brochure from the Schizophrenia Society and as I was leaving the hospital, and she said "You may want to phone these people."

* So it really helps coming to the society and talking to other people, because we see what's worked and what hasn't worked. I would have never been on AISH without the society. I was on welfare, and I never even knew about AISH. They don't tell you. They never tell you.

**Medication**

Medication is a central reality in the lives of people with schizophrenia. For medical professionals, it is clear that it is better to take medication to reduce psychotic symptoms and put up with severe side effects. But this trade-off is not at all so clear to the people who have to take the medications.

* They don't tell you. They don't tell you about your side effects. and the side effects are just incredible.

* 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 from them. They were saying this works.

* The medical profession calls our pharmaceuticals chemical restraints. It's really hard to explain to them how it feels when they give us too much. But it's like being tied up in certain areas of us.

* 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.
* The meds totally zonked me out, because my doctor medicated me to the ying-yang. I was a walking zombie. Somebody would ask me something, I’d go, “What?” That was the worst time.

* My doctor's in trouble tomorrow when I see him. I’m going to really give it to him with both barrels, because I changed over to olanzapine. He didn’t tell me it would take two and a half weeks to kick in properly, and for me to be stabilized on it

* I was concerned about my weight gain, and I'm bringing up this concern, and the doctor 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." After he left, I said “What is wrong with this doctor? Does he like making all his patients voluptuous or what?” And the nurse says, "I'll talk to him afterwards, that's really out of line."

**Treatment Experiences**

Group members also express frustration about times when they were not listened to or when they were not treated with dignity. We have divided this into 2 sections: doctors and institutions.

**Doctors:**
* I've had [my doctor] for years, and he's like, “She's healthy on these drugs.” This message I'm getting, it's not verbal. She's healthy on these drugs, she's out of the hospital, she's been healthy for years on these drugs and that's all they care about. I'm a guinea pig, that's all I feel like.

* My doctors are making me feel like it's a brick wall. I want to strangle my doctor but I can't, it's against the law. And until I change doctors, I feel like a guinea pig, and I'm hitting brick walls. It's very frustrating and I'm tired of feeling that way. I guess I just want to be heard about the subject.

* I've got this other doctor now and the first two times that I went to see him he was sitting there cleaning his nails. I told him that was down right irritating, and I didn't think he should be doing that while I was talking to him. Well, he quit doing that.

* It seems like the psychiatrists, their main thing is, is your brain okay and are you functioning mentally. Then after that they don't really care about side effects, physically what's happening, or anything else. You're not really treated as a whole person.

* I read another book. It says MD stands for Medical Deity. They think they're gods, you know, truly some of them do. Not my doctor, but some of them truly think they're gods, and what they say is gospel. And many times I've asked questions and they don't want to take the time. Or they think, “You're coming to an expert so you should just accept the advice.”
Institutions:
* I was in Claresholm. Claresholm is not nice at all. They put you in a room with someone who is a lot sicker. They lock the door of the bedroom so you can't even get in there. They think you would sleep too much, so they lock the doors on you.

* They hated it when I tried to sleep in the hospital. They wanted me to get up and do these activities, and that was the last bloody thing I wanted to do. They don't get it, we're there for a rest. Every other floor is there for a rest but they seem to think that we should be out jumping through hoops.

* I'd be sleeping on the floor in the hallway in Ponoca. Outside my door, with it locked. and my bed inside waiting there for me, a sick person.

* Going in the psych ward, it's like you're a criminal. They take away all your privileges. You go into hospital pajamas. I'm not a criminal, I did nothing wrong, I got sick. If I was a heart attack victim they would be catering to every need, but I'm in the psych ward… 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.

* I felt criminalized in the Foothills. 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.

Positive Experiences

In this next section, we describe group members’ positive experiences with medical professionals. Rather than dividing these experiences into our three main themes, we present these in one group. Good communication is central to these experiences. Good communication brings our main themes of diagnosis, medication, support, and treatment together in the lives of people with schizophrenia. When people get a definitive diagnosis and get information about the illness, about medications, and about available support, 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 look after themselves, and start to see ways to deal with their situation.

* Then I had a doctor bring everything out of me. It took him only three years, from 96 to 99. In that short period of time he brought everything right in front of me. He asked me one question and that was it. He asked me, “What do you need to feel better?” And everything came into place.
* The information I got from the Schizophrenia Society helped me understand what I had, because I was in denial. I mean from the very beginning I was totally in denial. "I don't have schizophrenia, I'm not weird, everybody else is," you know, that kind of thing.

* [My doctor] is my friend. He's actually made me well over the past twenty years. Doctor X has made me well for life.

[My doctor] knows how I'm feeling. He knows that I sometimes have my down days and my up days, and he knows.

* [My doctor sees me] for as long as I want. Sometimes it’s short because I tell him right off--- I’m doing this, I’m doing that, and this is how everything went and this is how I’m doing. And then other times I go, well, I don’t feel very great, and we sit and we talk about why.

*My experience this time when I was in the hospital was really different. My doctor was doing something with my medications and I was really upset. So he explained it all to me. And I said, “I understand why you made the change.” And he said “Thank you for understanding.”

* But you didn’t have in the eighties what they’ve got now…And even though the system now might seem to be not very good, it was a hell of a lot worse twenty years ago.

* 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. They want to see that the person they’re talking to is understanding them.

* You know what I think about your relationship with your psychiatrist? 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. He 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.

* I've been lucky I have a treatment team that really cared. The team really listens to me so that's good. But you know, still, it's like a parent when their child becomes sick, they don't want to give up any of the control. And I guess with the way the old system was, the psychiatrist had all the control. And now the pendulum is swinging back to the middle, where we're gaining some control back, so that's important. We need to have control. We need to have a working relationship. We both need to be respected for our opinions. So it has changed a lot. Before it was just “one way communication.” Now it's starting to be “two way.”

* I think the best thing that I’ve learned is to be assertive. If you don't want to do something tell them. I think that it's the nature of the beast, the more you learn about the beast, the easier it's going to be to deal with it. When we put ourselves in our doctor’s
hand, then we're at the mercy of his knowledge. I truly believe you have to know your illness, diabetes, schizophrenia, Parkinson's, whatever. Take control of your own illness.

* You know, 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.
Recommendations

Good communication with medical professionals is essential in the lives of people with schizophrenia. Getting information about diagnosis, medication, and support and being treated with dignity and respect helps people with schizophrenia overcome denial, come to terms with having schizophrenia, and learn to live with the illness.

*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.

*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.

*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 won’t tell us. We deserve the same kind of information as other ill people.

*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.

*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.

*Don’t send us out of town to places like Claresholm where we are isolated from our support network of family and friends. This does not help us to get better. Find a way to treat us close to home.

*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.

*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.

*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.

We leave the last word to Dana, with one final quote from the interviews:

* You know what? I want them to listen a hell of a lot better than they do. Some are good, but……Not just psychiatry though, I’m talking all fields of the mental health system.