

## Rights, Research and Liberation

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By and large, mental health research has been designed, conducted and analyzed by professional researchers working for academic institutions. Methods are generally quantitative and based on the measurement of pre-conceived constructs (e.g. reduced symptom severity, relapses and re-hospitalizations, improved social and vocational functioning etc.). Little is done to increase our understanding about the importance of culture, meaning, context, politics, and power, and few studies are conducted (let alone, read) by people who are directly affected by the research outcomes

Most qualitative research methods focus on the meaning people make of their particular experiences and the ways in which meaning is negotiated through various relationships. Particular attention is paid to the cultures within which people live and the context within which experiences occur (historical, social, etc). Particular attention is also given to positions of power and privilege, language, and the dominant assumptions that contribute to the ways in which people describe their experiences. Often, people who are the “subjects” of the research are also the primary or co-researchers, and instead of professing value neutrality and objectivity, are explicit about creating change and challenging assumptions.

At a time, in mental health, when we are talking about “paradigm shifts” we forget that our methods and practices of research must also shift. Instead of focusing on individual illness constructs, we must focus on relationships, meaning, and social change (Mead & Hilton, 2001). Story telling is one way to broaden our discussion and our insights.

Storytelling has long been recognized as a way of both describing one’s self, differentiating one’s self from other people, and a way of making connections with others. The way stories are told is influenced by who is listening, the questions that are being asked, when and where the story is being told and how the storyteller hopes to impact the listener. Stories that are told in groups are impacted by each other and can help elicit some of the “yet to be told” stories. In other words, stories are a relational, dynamic phenomenon that can allow people to challenge their self-images and contribute to the ways in which their listeners/researchers/readers must challenge their own stories and the cultures within which their stories are constructed (Mead & Hilton, 2001). Following is example of this process.

A meeting was held at a peer support center to develop “outcome measures” for the peer center. I was invited to facilitate the process and to explain action and narrative research. To help us get away from the traditional research roles, I asked the group to talk about their experiences with other research projects they’d been involved with. Responses were unilateral; people had been “subjects” of the research, saw themselves in illness roles, had rarely seen research reports (which were difficult to understand at best), and were

quite sure that the outcomes of the research had made no difference in their lives. Furthermore, they had wanted to provide the “right” answers (even when the questions were nebulous), they had felt “less than,” and had felt uncomfortable knowing nothing about the researchers background, or whether they could ask about it. Research itself was intimidating.

I asked if people wanted to define for themselves, what peer support meant and how it should be written about or evaluated. Although there was some confusion and discomfort about the process, the group signed on. It was not going to be easy, I pointed out, to be both experiencing the difference peer support makes in your life while reflecting on that experience and the experience of others. We started talking about some of the ways in which the peer center had already made a difference in people’s lives.

This group had recently written, produced and participated in a play about stigma. Though the content of the play was important, some of the other outcomes were surprising and life changing. People told stories about getting “symptomatic” before a production and wanting to quit. As they talked among each other and with other members of the center, they began to realize, that in a different language, it might have been their version of stage fright. In fact this experience was the topic of the play and they were living it. By going through with the performance, not only did they push past their perceived limitations but they were also able to challenge their understandings and meanings of their “symptoms.” At the same time they put forth a living narrative which challenged the audience’s assumptions and understandings. As the play continued to be performed, it was less scripted and more evolving. Participants began to realize that the play was less about stigma education and more about role changes, relational growth and social change. By telling their stories in new ways again and again stories became re-constructions and the peer center began to make some cultural shifts and build a new community identity.

After sharing the story about their play we talked about some of the ways people had chosen to tell their story in the play and how they thought they had learned to tell that story. We talked about how their self-perception, relationships and understanding of “mental illness” had changed and we talked about how we wanted to document and analyze this “data.” Emerging themes we chose to focus on included changes in language, risk taking, building deeper relationships, challenging some of the traditional mental health practices, and becoming more involved in the peer center as well as the larger community. The process of exploration needed to include taking weekly actions (risks in relationships, trying new things, challenging aspects of their treatment etc.) and reflecting upon why they had chosen those particular actions, as well as the changes those actions evoked. The format would be journal, and/or taped discussions. “Validity” testing would be done by different members of the research group playing the role of devil’s advocate (Reason, 1989). Through this process, other members would be part of the conversations, asked to join in the research, and a community “story” would be written. Our hope was that, because theatre worked so well for this community, that other artistic forms might become part of the research.

This is only one example of the ways in which research can expose more complex systems at work. For mental health this has implications that have, up to this point, been seriously overlooked. Those of us who have been labeled with mental illness exist in cultures where meaning is imposed on us. We have taken on roles and identities that keep us separate and feeling “other-than.” If our research is to have real meaning, we must all become “reflective practitioner” researchers (Schon, 1983) on ourselves and with each other. We must not let ourselves be reduced to arbitrary constructions and we must not let someone else tell our stories and have control over who we become. The goal of our research must be to empower all those involved (researchers, participants, and readers) to move away from the “reified” conclusions that traditional research has drawn (Bentz and Shapiro, 1998). In that, we must all be willing to challenge our assumptions and perceptions, have new “conversations,” and continuously build new ways of creating knowledge together.

References:

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