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BRIEF REPORT

Mental Health Consumers and Providers Dialogue in an Institutional Setting: A Participatory Approach to Promoting Recovery-Oriented Care

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Objective: This brief report presents the preliminary findings of a participatory project, to answer a question raised by stakeholders in mental health services: How can providers and patients create a process for knowledge exchange to support recovery-oriented care? ***Method:*** Participatory action research (PAR) and narrative phenomenological methodology guided the selection of methods, which consisted of an iterative process between telling stories and dialoguing about personal values related to recovery. The sample consisted of three occupational therapists, a psychiatrist, an academic–clinician, and five consumers of mental health services who were involved in each stage of the research, including design, interpretation, dissemination, and implementation. ***Results:*** Significant interpersonal and intrapersonal tensions were named, and conditions for a more sustainable process of knowledge exchange were explored. ***Conclusions and Implications for Practice:*** The project revealed both the challenges with situating research within an institution (hierarchy of knowledge, power, and vulnerability) and face-to-face dialogue, as well as positive changes in professional attitudes and consumer empowerment, as providers and patients came to understand what was at stake for each other. The project underscored the need for provider–consumer dialogue as a process to explore tensions and values in promoting recovery-oriented care.

Keywords: participatory action research, recovery-oriented care, system transformation, consumer-centered services

A recovery paradigm promoting consumer empowerment and involvement in service development is an international guiding principle for the transformation of mental health care (Mental Health Commission of Canada, 2012; World Health Organization, 2010). Yet, the gap between policy on recovery and its implementation remains problematic. First, conceptualizations of recovery are unclear (Le Boutillier et al., 2011), as they consist of a range of subjective and objective dimensions (Whitley & Drake, 2010). Second, stakeholder values are fluid, shifting across time and according to context. The complexities of social and contextual factors in recovery-oriented care and the divergence in definitions and measurement thereof challenge the implementation and evaluation of recovery. Although the meaning of recovery has been examined from consumer (Piat, Sabetti, & Couture, 2009) and

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provider (Piat & Lal, 2012) perspectives, we found no studies to date that examine how such meaning is constructed and negotiated in the context of actual consumer–provider interactions within an institutional setting.

For our group of consumers and providers, this raised the research question: How can we create a process for patient–provider dialogue in order to shape recovery-oriented care in an institutional setting? The aims of the present study were: (a) to identify consumer and provider values of recovery and (b) to see if and how consumer–provider dialogue might function in an institutional setting.

Method

In line with the Canadian endorsement of integrated knowledge translation, which emphasizes the participation of relevant stakeholders (Canadian Institutes of Health Research, 2010), we used participatory action research (PAR) and narrative phenomenological methodology. PAR focuses on (a) creating positive change or action through (b) the collaborative and equal involvement of stakeholders in the research process (Walter, 2009), which requires "critical dialogue and collective reflection" (McIntyre, 2007, p. 1). As a research methodology, narrative phenomenology focuses on how stories work as actions when the teller and the audience of these stories come to understand what matters most to the other, and thus, enter into a new social contract (Garro & Mattingly, 2000). Combined, both of these methodologies focused our attention to (a) building the trust necessary for collaboration, and (b) integrating the often tacit expertise of both consumers and providers that became explicit through dialoguing about stories.

Sample and Site

In line with PAR methodology, our sample consisted of the participants who had raised the initial research question. This included five consumers (two of whom are certified as peer support workers), three occupational therapists, one psychiatrist and a clinician-researcher affiliated with a university. The consumers had extensive knowledge of the system, experience with different stages in recovery from serious mental illness, and a desire to promote social change within the institution. The providers had experience with the development and delivery of rehabilitation services and a similar interest in social change. The site was an outpatient mental health clinic in a university hospital, at which services were provided by a team of medical professionals and designed for individuals with complex pharmacological or psychosocial needs. Institutional values in this setting were largely shaped by biomedical models of care and research. The study received ethics approval through a university ethics board.

Data Collection and Analysis

At the initial meeting, the principles of PAR were addressed in relation to our specific context. The group agreed to the overall aims of the study, timeline, and procedures, which involved weekly discussion groups over a period of 4 months. Each session would last 90 min with two 3-hr final sessions in which content and process could be reviewed and future actions could be explored. We agreed to use stories to understand what really matters in recovery from both provider and consumer perspectives (Mattingly & Lawlor, 2000). Dialogue (Isaacs, 1999; Schein, 2003) would then be used as a vehicle to critically reflect on the values elicited in these stories. Participants generated topics they felt were most relevant to discussions about recovery, which we then integrated into three themes: (a) relational space (boundaries, relationships, limited resources, shifting roles, power); (b) obstacles (stigma, culture, fear of exposure); and (c) meaning making (what is recovery?).

Initially, we had proposed a structure of telling stories during two sessions, followed by a session of dialoguing about the underlying values in the recounted experiences. After the initial two sessions, participants expressed that the structure lacked fluidity. This led to an iterative pattern in the sessions of generating data (telling stories) and analysis (dialoguing about values or what mattered and the underlying assumptions). All sessions were audiotaped, deidentified, and transcriptions were made accessible to all participants. After this 10-week process, the participants analyzed these sessions for primary themes (Braun & Clarke, 2006) and values in the form of excerpted sections of text or dialogue. These preliminary analyses were then circulated for member checking and discussed across two half-day sessions. A secondary analysis occurred during the preparation of reports, conference presentations, and dissemination. In this article, we present our preliminary findings. Analyses are ongoing as the participants continue to meet for further dissemination and planning purposes.

Results

Initial collaborative analysis revealed a complex interplay of tensions between provider and consumer values, which were often exemplified by the conflict between the values of beneficence and autonomy in medical ethics (Pellegrino & Thomasma, 1987). Providers frequently voiced stories about the intrapersonal conflict between the "need to protect" and the desire to support consumer autonomy. Challenges in balancing providers' specialized knowledge with the experiential knowledge of the consumers in their care were also revealed. As one consumer summarized, "I discovered that the idea of consumer empowerment is difficult for the clinician, who must give up some of his or her own power, and at the same time, readjust the understanding of responsibility toward the client."

Consumers frequently voiced stories about feeling misunderstood and emphasized the need for their *experiences,* rather than their symptoms, to be acknowledged: "If you're a crazy person and you scream, that's all they hear is the scream . . . and you're pathologized for being angry and having an emotion." Consumers also felt that providers' stories took down the "shields of the profession and helped humanize the field of psychiatry. Although stories provided a vehicle for consumers and providers to understand each other's experiences, participants underlined the sense of vulnerability and potential for dissonance inherent in telling and witnessing personal stories. As one provider reflected, "I'm more confused and frustrated now, which isn't necessarily a bad thing," and then also commenting on the transformational potential of the process, "sometimes we're clear because our beliefs haven't been challenged."

Overall, the research process, as one provider summarized, sensitized "us to the gray areas in these [consumer–provider]

relationships." This sentiment represented a departure from the ideas expressed in initial sessions when providers' stories illustrated the tension between the desire for connection with consumers and the need to "maintain professional boundaries." Some participants felt that the process would have been easier outside of the institution where, as one consumer reflected, providers could "just take off their labels and see what's going on." With time, as one provider concluded "despite understandable and predictable apprehensions we appeared to have settled in a zone of relative comfort, enough, for example, to tell personal stories of worrisome life experiences, painful memories, voice hopes and critical views." As examples of personal transformation, one consumer mentioned having greater confidence in questioning policies and sharing ideas, and a provider began to change the nature of her conversations with her clients. "I realized that I still assume too much about the issue of power and autonomy and that I need to encourage dialogue with my clients. I assume that a client wants full control of his or her care and autonomy, but as I heard in the group, sometimes they want structure and need to depend on clinicians for support."

Not only did personal transformations occur, but also action-based outcomes: the inclusion of consumers as key lecturers on mental health in educational institutions, a community-based antistigma campaign, a presentation at a psychiatric hospital, a national occupational therapy conference, and a scheduled presentation at an international qualitative research conference. Experience gained through the project also led both consumers and providers to engage with other researchers on projects related to user-led research, stigma, and social inclusion.

Conclusions and Implications for Practice

The project revealed that (a) naming and addressing inter- and intrapersonal tensions, (b) exploring divergence in values, (c) openly addressing clinical concerns and risk, and (d) including people with lived experience of mental illness in the design and delivery of services, can facilitate recovery-oriented care within institutional contexts. Although the project was small, it did illustrate that consumer–provider partnerships were possible within the walls of an institution. An ongoing dialogue group in the organization was recommended as a way to address needs, values, and shifting mandates. Including other stakeholders, such as administrators, caregivers, and policymakers, was suggested as a way to promote sustainability, but the impact of infusing such dialogue into the organizational culture remains unknown. Mental health research would benefit from implementation studies that investigate how to involve stakeholders in changing practices, as well as how to create safe conditions for dialogue and collaborative processes.

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