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Mental health consumer concept mapping of supportive community

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ABSTRACT

This research engaged consumers with severe and persistent mental illness receiving services in the public mental health sector in creating a comprehensive list of 110 needed community services and supports, then individually sorting and rating these items. Within the resulting concept map generated by Concept System software and as interpreted by the study participants, successfully living in the community is actualized when there is an outer layer of support regarding basic needs; financial means; individualized, comprehensive and available services; competent and caring staff; community education; legal rights enforcement; and social change directed at dismantling the discrimination and stigma associated with mental illness. Peer support and services is critical component, providing a transformational space from basic survival into recovery, supporting personal development and skills building and further social development. This study demonstrates that adult public mental health consumers actively receiving services can engage in collaborative research in meaningfully determining what their needs are, conceptualizing what the services should be and how developed, and articulating service prioritization.

1. Introduction

Mental health systems have increasingly recognized the importance of attending to the views, perspectives, and self-perceived needs and preferences of consumers/survivors of public mental health services. These perspectives often differ from those of providers, leaders, care givers, and family members (Kikkert et al., 2006; Nelson, Lord, & Ochocka, 2001; Ridgway, 1988; Russinova, Rogers, Ellison, & Lyass, 2011; Wadsworth & Epstein, 1998). Such differences regarding the needs and preferences for services and supports, the barriers that exist to obtaining them, and the relative importance of outcome goals can run counter to recovery (Campbell, 1998; Glajz, Deane, & Williams, 2017; Onken, Dumont, Ridgway, Dornan, & Ralph, 2002; Piat & Lal, 2012). Longitudinal research has demonstrated that consumers can live meaningful and successful lives (Carpenter & Kirkpatrick, 1988; DeSisto, Harding, McCormick, Ashikaga, & Brooks, 1995; LeCroy & Holschuh, 2012; Mueller et al., 1996), and have a resiliency at times overlooked by programs and systems (2004, Campbell, 1998). But most consumers continue to face significant personal and political barriers in their efforts to have their voices heard and their expertise valued (Chowanec, Neunaber, & Krajl, 1994; Hyde, Bowles, & Pawar, 2015; Nelson, Lord, & Ochocka, 2001; Stromwall, 2002).

At the same time, community integration is increasingly being defined as essential to recovery, and community connections further resiliency resources. Mental health studies have explored specific practices or social characteristics that may contribute to community integration (e.g., Bond, Salyers, Rollins, Rapp, & Zipple, 2004; Wong, Matejkowski, & Lee, 2011), empowerment (e.g., Nelson et al., 2001b) and the meaning of community and community involvement (e.g., Bromley et al., 2013). Yet basic questions as to what consumers identify as needed community supports to be successful in community remain unanswered.

Concept mapping has been used to explore substantive issues as well as for planning and evaluation contexts in mental health (Bedi, 2006; Gol & Cook, 2004; Johnsen, Biegel, & Shafran, 2000; Marquart, Pollak, & Bickman, 1993; Paulson & Worth, 2002; Rosas, 2005; Trochim & Cook, 1992; Trochim, Dumont, & Campbell, 1993; Trochim, Cook, & Setze, 1994; Weeghel et al., 2005). The Dutch, who include addiction services as mental health care, apply it most frequently (see Kikkert et al., 2006; Nabitz, van Randeraad-van der Zee, Kok, van Bon-Martens, & Serverens, 2017). The participants or stakeholders generally consist of a heterologous mixture of mental health providers, leaders, advocates, care givers, family members, and/or service recipients (consumers), often providing a way to find common ground or definition and move towards consensus.

But the small number of service recipients (consumers) involved in these efforts limits the heterologous mixture that is found among consumers. Arguably the group with the most at stake is the one with the

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least number participating in the concept mapping process. Their perspectives may be divergent from and deluded by the competing or shared perspectives of mental health providers, leaders, advocates, care givers and family members. In fact, it is often these interest groups that recommend and help select which service recipients to involve. In a review of the refereed published concept mapping articles that focused on mental health, no methodology was found that reported randomly selecting service recipients or having service recipients themselves chose their participants. Mental health consumers continue to have a limited impact on empirical studies, because people who experience psychiatric disorders have been excluded from the process of research investigations (Kaufmann & Campbell, 1995; Nelson et al., 2001b).

Concept mapping is particularly strong, however, in regard to the participatory and democratic nature of the process. Each participant has opportunity to provide input and there is allowance for reasonable estimates of the time necessary to complete the process (Burke et al., 2005; Kane & Trochim, 2006). These characteristics are important for creating an environment where mental health consumers willingly share their perspectives (Dumont, 1993; Kaufmann & Campbell, 1995; Trochim et al., 1993).

1.1. Research questions

It was with this hope that the concept mapping methodology was used in a public mental health service setting to tap a heterologous, more representative sample, of service recipients in an effort to conceptually capture a map of supportive community from the perspective of those with lived experience of severe and persistent mental illnesses. Specifically, (1) what do people with serious and persistent mental illness identify as the community supports they need, (2) how do they conceptually group and prioritize these supports and (3) what insights might they reveal as to how the community engagement and integration process manifests itself? An accompanying aim of this study is to (4) capture and describe the process used and (5) the resulting lessons learned when all the stakeholders (participants) have the experience of severe and persistent mental illness, ranging from very recent psychiatric inpatient acute care to sustained tenure in the community, from current homelessness to peer leadership.

2. Methodology

The study was conducted in a public mental health outpatient center in a mid-size Southwest urban community where the majority of service recipients where on Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) and covered by Medicaid. The study used Concepts Systems software to conduct concept mapping, a structured process incorporating qualitative and quantitative methods to capture an interrelated pictorial view- or map - of participants input on a focused topic or interest (Trochim & McLinden, 2017). The Concepts Systems methodology is well developed, vetted and described (Kane & Trochim, 2006; Trochim & McLinden, 2017; Trochim, 1989a) and includes brainstorming, sorting, rating, two-dimensional multidimensional scaling (MDS) and hierarchical cluster analysis. Participants are actively involved in structured interpretation session designed to determine whether the map makes intuitive sense, labeling it in a substantively meaningful way, and discussing what the map might imply about the ideas that underlie its conceptualization.

2.1. Subjects

This study involved collecting data from consumers with serious and persistent mental illness. The recruitment process was done in four groups to maximize the heterogeneity of the sample – from recently released inpatient care to long term community tenure to consumer leadership. Each group was intended to yield between 10 and 20 people which Trochim (1989a) found to be the most workable size as it ensures a variety of opinions and ample group interpretation.

This study used two different approaches for sample selection. One group consisted of consumers in leadership and advocate roles or who were affiliated with consumer organizations and self-help groups within a Local Mental Health Authority (LMHA) region. This selection of participants was not random. The consumer leaders of these groups identified and invited members to participate. In particular, they asked those whom they viewed as having a “big picture view” of the challenges faced and supports needed people to move beyond mental illness and into meaningful life within community. The final sample N for this group was 19, but only 13 actually completed the steps necessary to be included in the analysis (68%).

The other three groups were pulled from the open caseload of this participating LMHA as stratified by length of community tenure from last psychiatric hospitalization (10 weeks or less since last the hospital stay, 6–11 months, and 18–26 months) and included all consumers in each of those strata. Stratification was based on community tenure in an attempt to capture a more complete picture of the possible range of community service and support needs that consumers may have. It allowed participants in each stratum to focus on that part of the system in which they were currently engaged. The total sample consisted of 177 consumers, randomly ordered within each stratum. Trained research volunteers from the LMHA’s homeless outreach staff contacted all 177 consumers and 48 of these consumers consented to participate in the study (27%), but only 35 actually completed the steps necessary to be included in the analysis (20%). Some consumers were screened out if they were not English fluent (16), a resource limitation of the study, or not able to give informed consent (8) to participate in the study.

How representative was the LMHA sample? Using the State Mental Health Authority’s information management system (IMS), a data file was created for the full sample that included the variables sex, race/ethnicity, age, and primary diagnosis. The IMS primary diagnosis was linked as closely as possible to the time of study participation. Chi-square tests were used for all four variables and none were statistically significant as to differences in the participants (35) versus non-participants (142).

2.2. Sample description

Participants completed a brief questionnaire containing two parts: demographic characteristics (Table 1) and psychiatric history (Table 2).

Table 1
Participant Demographics Characteristics.

		LMHA Sample	Consumer Group Sample	Total
Sex	*Male*	15	4	19
	Female	20	9	29
Age	*20–34*	9	2	11
	35–42	9	2	11
	43–47	10	4	14
	48–63	7	5	12
Primary Language	*English*	33	13	46
	Bilingual	2	0	2
Race/Ethnicity	*White*	20	13	33
	Other	15	0	15
Marital Status	*Married*	2	3	5
	Never	18	4	22
	Other	15	6	21
Monthly Income	*≤ $500*	19	1	20
	$501–750	12	5	17
	≥ $751	4	7	11
Living Situation	*On Own*	18	9	27
	Spouse	1	3	4
	Adult Relative	6	0	6
	Other Housing	9	1	10
	Homeless	1	0	1
Totals		35	13	48