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Health Care Professional's Opinions on Culture and Rehabilitation Services for Youth Experiencing Early Psychosis

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Disclosures
The primary investigator/author was the clinical administrator of at the site during the duration of the study. The results were intended to inform service delivery improvement. I guarantee my sufficient participation in the planning, design, analysis, interpretation, writing, revising, and approval of the manuscript. Julian Bergeron is acknowledged as research assistant for this project. McGill University's Faculty of Medicine Summer Research Bursary Program funded this project.
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Abstract

Background. Early intervention programs for youth experiencing early psychosis aim to facilitate access and community reintegration. Yet, the Mental Health Commission of Canada has identified stigma and discrimination in accessing and receiving mental health services as one of the primary obstacles to the community participation of persons with mental illness. **Purpose.** To explore the opinions of expert health care professionals on the service barriers to community integration for youth with psychosis, in order to inform the improvement of a rehabilitation program. **Methods.** Interview-based qualitative descriptive study (n=6) analyzed within the person-environment-occupation template. **Findings.** The primary barriers to community participation are described within sociocultural environments. Specifically, the lack of culturally informed practices within clinical and rehabilitation care significantly contribute to client access and involvement in rehabilitation programs**. Implications**. Cultural sensitivity and competency training for therapists can help to move policy into action for family-focused, values-based, early intervention rehabilitation practices.

Keywords: Early intervention in psychosis, occupational therapy, cultural sensitivity, person-environment-occupation, family

Introduction:

The role of occupational therapists and other rehabilitation professionals within the mission of early psychosis intervention is to prevent or attenuate the devastating effects of psychotic-spectrum disorders in youth. This is known as 'secondary prevention' whereby the psychosocial sequelae of psychotic illnesses, such as unemployment and loss of social networks, are targeted and minimized to improve recovery and long-term outcomes (Jackson & Birchwood, 1996). In 2005, the International Early Psychosis Association and World Health Organization (W.H.O) issued a consensus statement promoting community reintegration as part of comprehensive early psychosis programs. The defined outcome is "2 years after diagnosis, 90% of affected individuals have employment/ education rates similar to their age-/gender matched peers" (Bertolote & McGorry, 2005, p. S116). The current literature indicates that functional recovery lags behind symptomatic recovery: Clients in treatment achieve low social and vocational functioning after 6 months, or even 2 years, of their first-episode of psychosis (Robinson, Woerner, McMeniman, Mendeloqitz, & Bilder 2004; Tohen et al, 2000).

Canada has seen a nation-wide series of policy reforms to address mental health care and services. In 2006 the Kirby Report identified stigma and discrimination in accessing specialized services as one of the primary barriers to the community participation of persons with mental illness (Kirby & Keon, 2006). Within this changing landscape, the author initiated an appraisal of the rehabilitation needs of youth followed in an early intervention in psychosis program at a Canadian urban university teaching hospital, beginning in 2007. A randomized chart review of 50 individuals followed by an occupational therapist in an early intervention program revealed that attainment of productive occupational roles was 32% at 1 year, 42% at 2 years and a fluctuating 65% at 3 years between 2005-2007 (Zafran & Laporta, 2008). This is compared to an 85% employment rate in Canada for youth 15-25 y.o. (Galarneau, Morissette & Usalcas, 2013). Although this early intervention program's outcomes are comparable to other early intervention services, this is well below W.H.O standards.

Identifying local service barriers to functional outcomes is a direct way of subsequently designing services. Although several barriers can be deduced from the literature to date, it was unclear which barriers would be a priority to target in occupational therapy and/or psychosocial rehabilitation interventions that aim to rehabilitate and reintegrate patients within their particular contexts. Specifically, these services are offered in an urban, cosmopolitan city with the third largest foreign-born population in Canada (Statistics Canada, 2006). Having been mandated with the re-design of services, the author posed the following research question: From the perspective of health care professionals, what are the personal, environmental and occupational factors that affect services targeting the community reintegration of help-seeking youth treated in this early intervention program service?

Methods

A qualitative study based on a semi-structured interview was designed to elicit experienced health care professionals' opinions of the factors affecting services for the community reintegration of young adults experiencing early psychosis.

Sampling

A purposive sample of health care professionals with greater than 5 years of experience in either early intervention or in youth psychiatric rehabilitation services were invited to participate in this study at the site in question. They were purposefully chosen as having experience within the domain of inquiry as well as being employed at the institution within which services were being appraised. Following the hospital's institutional review board ethical review and approval, study objectives were announced at team meetings and a one-time email invitation was sent to the nine persons at the study site identified as fitting these inclusion criteria.

Data Collection

The semi-structured interview questions were developed to directly address the research question. After an initial pilot run with a psychiatric rehabilitation clinician, primary questions were re-phrased and simplified into components to ensure relevance and clarity (see Table 1). Once a complete description of the study was provided, and written informed consent obtained, audio-recorded interviews were conducted. Participants were interviewed during the summer of 2009 in the privacy and convenience of their offices during their lunch hour, for a maximum of 75 minutes. To minimize conflicts of interest and interviewing issues related to the author's administrative position at the site, an external research assistant conducted the interviews. The research assistant maintained a post-interview journal to promote a reflexive stance.

Table 1: Sample of interview questions

What does 'community reintegration' mean to you? Can you share a specific example from your clinical practice?
We define a "barrier" as anything that might limit functioning and/or community reintegration. In your opinion, what are the barriers to reintegration for youth experiencing early psychosis?
Please describe how you think our services facilitate community reintegration
In your opinion, what elements of our rehabilitation services need to be improved in order to support the community reintegration of this client group?

Data Analysis

Data analysis was undertaken in a two-tiered iterative process. Following repeated immersive listening, transcription and note taking, an inductive qualitative description of the de-identified and transcribed data was undertaken for each interview (Sandelowski, 2000). That is, descriptive codes were generated for each interview, with the research question as focus, then across interviews. The descriptive codes were returned to iteratively to consider which ones might be grouped together for higher-level codes, kept as is, or descriptively refined. For example, all participants described substance use by their clients, and this was initially coded as a barrier to community reintegration. However, upon further exploration of the opinions and perspectives of the participants about this barrier, what became clear was that substance use, and being involved in an alternative subculture, can sometimes be an area of peer success for youth with first episode psychosis who might be struggling in school. Therefore, this was reframed within the theme of meaningful activity, even if medically risky. This first step of descriptive coding was completed independently by the research assistant and author, and then compared and refined. A summary statement of the themes from each interview was presented to each of the interviewees to verify if the analysis had authentically captured what they intended to convey.

Across-interview themes were then deductively examined within a template analysis where a theoretical categorical scheme was used to organize the thematic data (Miles & Huberman, 1994). The template chosen to provide a rehabilitation-specific structure was the "Person-Environment-Occupation" framework (PEO; Law, Cooper, Strong, Stewart, Rigby & Letts, 1996). The three elements of this template are defined as follows: Person: "What is it about the person that should be our primary concern?" (Bruce & Borg, 2002, p.25). In this study, this category relates to the opinions of health care professionals about the experiences of their clients with a first episode of psychosis. Environment: "Therapy, like occupation, never occurs in a vacuum – it occurs in a lifespace…composed of other people, their beliefs, and values" (ibid, p.42). This category refers to the opinions and reflections of the participants about the services they offer as well as their conceptualization of 'community reintegration'. Occupations include activities and tasks that are grouped meaningfully together, and which the participants deemed important for their clients and their families. The PEO was chosen because it is a framework broad and flexible enough to encompass multiple potential facets of the results, as well as having a transactive approach to understanding processes that affect meaningful engagement within the community (Bruce & Borg, 2002).

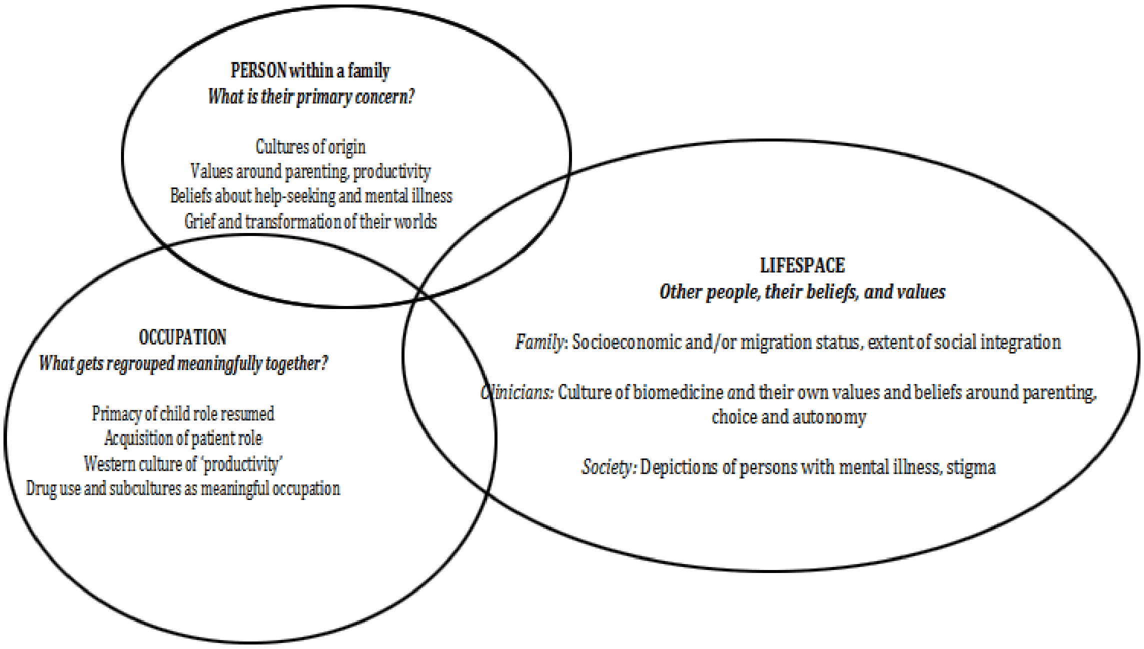
Collaborative debriefing occurred throughout between the research assistant and author to promote reflection. Transparency was maintained throughout with a detailed audit trail of the analysis process. To promote rigor, the PEO components and model emerging from this study were presented to the research participants as a group, with ensuing discussions and feedback adding depth to the results.

Findings

This study took place at a Canadian urban teaching hospital within its outpatient psychiatric department. Six Canadian female participants consented to participate. They were from the disciplines of social work (1), nursing (1) and occupational therapy (4). The three potential participants who refused to participate due to time constraints were a nurse and two psychiatrists. The six participants had between 7 to 40 years of clinical experience in adolescent and/or youth psychiatry. They were all involved in early intervention for psychosis services and/or outpatient rehabilitation services for youth with psychosis at the time of the interviews.

Although culture was not an explicitly targeted domain of inquiry, when examined in depth in the first tier of descriptive analysis, all the participants spoke in several different ways about culture, even when they had varying opinions about how best to approach this dimension. Culture was variously conceptualized by the participants as natal language or country of origin, as family and/or community-based values and ways of engaging in the world, as well as a way of seeing and understanding the world. The participants spoke of the culture of clients and their families, cultural expectations of occupational productivity, clinical cultures of care, and their own values. This led to findings that focused on the sociocultural dimensions that affect and inform the access, design, content and delivery of early intervention rehabilitation services (see Figure 1).

Figure 1: Sociocultural dimensions informing early intervention rehabilitation services



Occupation. “Society is not designed for people that can’t perform like everybody else”.

Participants spoke of witnessing the struggle of young adults in becoming patients and resuming a child role. It was stated that it might be hard for the parents to know what is best for their child who is still trying to develop as a young adult. Many different scenarios were evoked, including large cultural variations in parenting and occupational expectations that cannot be predicted by ethnicity alone. In the participant's experiences, there are parents who directly ask them "when to push their child to do things, and when to step back and not stress them out" as well as families and "youth who pretend to be 'ok', who fake being recovered" and do not speak openly of their difficulties, due to different beliefs and values around mental illness, and the experience of becoming a patient. The use of drugs was described as a "coping mechanism…or maybe a bit more than that," with descriptions of drug use as an alternate meaningful occupation when other occupations are lost, for example when having to stop school due to an episode of psychosis.

Person within a family. "The one (social support) with the most influence is the family". Every participant expressed the opinion that the family is central for the client. The participants' interpretations of the client and their family's presenting motivation and engagement also determined the extent of clinician involvement and array of services offered, because "a young person interested in participating in our rehabilitation program" is perceived as having a better prognosis in terms of community outcomes than one who may decline such services. Differing cultural idioms of distress and parenting were acknowledged, "it's not always our social norms of behaving," yet without much discussion about how to then tailor services. For example, some parents may "prefer that their kid is on drugs than mentally ill", while other families may adhere to the notion that medications denote illness and are not acceptable. A concern voiced was whether the family might be over or under involved, dependent on their ethnic and/or socioeconomic backgrounds: "if the parents are over-protective, that's not good, but if they're not present enough, then he [the patient] will be lost…it kind of depends on where they're from".

Life space. The participants referred to the geographical and social spaces in which the person is engaged in on a daily basis, such as school, work and neighborhoods. It was stated that "the culture, quality and type of community support" is more important than the quantity in fostering a sense of belonging. Lack of community inclusion of the family as a whole was seen as diminishing the networks and opportunities that youth have to reintegrate socially and vocationally. This is especially the case in terms of the kinds of neighborhoods people can afford to live in. As one interviewee explained, "many people with schizophrenia are poor". When the person with psychosis comes back to a community, they "need to just fit in" and have an available circle of friends or mentor. Having a "strong attachment to a positive person in life" was seen as key. If the client's parents know a lot of people in the community, the client "may be accepted because he is so and so's son" in contrast to the community message that it is the family or individual's "fault" that they became unwell

Several interviewees strongly expressed their belief that persons need to both feel and be respected by health care professionals. The "message that we (professionals) give them" also plays a big part in their rehabilitation. Several participants believe that "we move too fast, we underestimate the time it takes to grieve" in institutional cultures focused on efficiency and demonstrable outcomes. Three interviewees were critical of the lack of investment and time offered to clients and their families "to create meaning out what has happened, and is still happening within the health care system... we're quick to medicalize their problems, sadness, and reactions rather than understand and address them."

The belief endorsed by biomedical culture that a "schizophrenic can only do certain things" was lamented as being an unaddressed problem in clinical settings. "Sometimes we don't believe in them enough, and put them on welfare too soon, and then everyone's stuck with these rules and regulations around welfare and return to work which make it hard to come off the social disability, especially if they come from families with little money."

Participants said that "we don't always understand their [client's] culture" and in counterpart "they don't know our language, what we mean when we use certain words". The ability to connect with clients and their families leads to different services being offered, for different reasons such as " it depends if their family comes with them to advocate for them", if professionals "underestimate the time it takes to mourn" and even that "the rich and the poor [clients] are treated differently". If the patient has "money, education, a family member that comes with them, [if they're] good looking, [have] education...” the participants described that clinician’s attitudes – including their own – would shift in terms of how much to invest, and what. Even “the [home] address makes a difference”.

Different participants also had their own values around how they believed people should behave when faced with an illness. For example, one participant said, “well, if the person is a fighter, they’ll do better”; yet, another participant was more cautious, stating, “motivation can be very complex, it’s not always a medical thing or a personality thing. Wanting to move forward, to engage, there can be so many reasons why… we don’t focus on their experience to understand it all.”

Finally, all the above was described as being embedded in larger socio-cultural beliefs and practices. All interviewees lamented the presence of negative stereotypes of mental illness in movies, books and social media, with widely differing beliefs such as “we should be doing public anti-stigma education workshops as part of our job” or “I’m not sure what I [as a clinician] can do about this”. Stigma was the main environmental concern for five of the six research participants. “It [stigma] is a really big one, big in the sense it is very important and big in the sense of it being widespread”.

Discussion

This qualitative study highlighted the social and cultural complexities faced by a pilot sample of health care professionals in providing tailored rehabilitation services to youth experiencing a first episode psychosis, and their families, where culture “may be conceived of as the lens through which we perceive and interpret the world around us” (Hunt, 2007, p.229). The cultural origins of patients were linked to direct challenges, such as language barriers, immigration or refugee paperwork, and medical coverage, as well as more subtle and invisible processes such as differential services being offered to different patients and their families. Rehabilitation efforts occur at the complex interface between clinical cultures of care, individual clinician’s own cultures and values, and a culturally diverse clinical population. A young person or the family may resist, collaborate or be overwhelmed by their experience; and in turn, their culturally informed values and responses form their path through rehabilitation programs.

In shifting the culture of psychiatry into a more recovery-oriented culture of hope this study opened the very real question of the ability of clinicians at this particular site to communicate and connect with young adults and their families from very different backgrounds and beliefs. Canada’s mental health strategy priority 4.2 addresses the issue of tailoring mental health to a diverse population by stating that “too many people from the immi¬grant, refugee, ethno-cultural and racialized communities that make up a large part of Canada’s population do not have access to services, treatments and supports that feel safe and are effective because they are attuned to that group’s culture, experience and understanding” (MHCC, 2012, p. 82). The opinions of these six health care providers reveal how “racialized assumptions and biases are historically embedded into the very DNA of health care delivery systems and shape interactions and outcomes” (Metzl, 2010, p.202). For example, how clinicians interpret key rehabilitation concepts such as engagement and motivation in goal setting, as expressed by clients from various cultural backgrounds and beliefs, can significantly affect access to, and the design of, a rehabilitation process (Hunt, 2007).

Rehabilitation practice requires “actively taking diversity into account race, culture, age, sexual orientation, and other issues of difference that impact occupation and occupational performance”(CAOT, 2007, p.29). Mattingly has described how the rehabilitation experience of clinicians and African American families of children with physical disabilities can be understood as crossing cultural borderlands (Mattingly, 2010). This pilot study suggests that these same cultural and narrative aspects of clinical reasoning are necessary in the design and delivery of rehabilitation programing for young adults experiencing early psychosis, and their families. The implication for practice that emerged from this study is the utility in conceptualizing rehabilitation services as a lifespace of people, values and beliefs. Thus, at the study site, there was a need for occupational therapists and other rehabilitation professionals to develop culturally safe rehabilitation spaces, as well as skills in providing family-oriented rehabilitation that take into account each person within their family and family values. These skills and attitudes range from cultural sensitivity and a reflective awareness of how one's own culture influences how care is interpreted and provided, to formal training in cultural competency skills (Hunt, 2007).

The main limitation of this study is its small sample size therefore theoretical saturation was not achieved for its pragmatic purposes. In addition, the perspectives of clients and their families would be necessary in further understanding and tailoring rehabilitation service programing aimed at community participation. Future research examining how early intervention rehabilitation approaches can facilitate community reintegration from a culturally informed point of view is key to improving services.

Conclusions

This qualitative study sought to explore the opinions of health care providers about the factors affecting community reintegration services for persons after a first episode of psychosis. The results were intended to inform occupational therapy and rehabilitation service design and delivery at a specific location. The main conclusion offered is the need for cultural competency training and the development of occupational therapists' skills in providing family-focused values-based rehabilitation practices as an integral part of holistic early intervention services.

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