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Association of Participant Preferences on Work and School Participation after a First Episode of Psychosis

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Abstract

Aim—To explore baseline ratings of importance (ROI) across life domains for participants in the Recovery After an Initial Schizophrenia Episode Connection Program (RAISE CP), and investigate whether ratings were correlated with intervention outcomes over time.

Methods—At baseline, 63 participants rated the importance of reducing symptoms, side-effects, confusion, increasing energy and school/work functioning and improving social relations. ROIs were examined in relation to work/school participation (n=41) and occupational functioning (n=37) after 12 months. Participants' mean age was 22.3 (±4.2).

Results—The ROI domain rated as most important was school/work functioning, and higher school/work ROI at baseline predicted work/school participation after 12 months of participation.

Conclusions—It is particularly important to assess participant preferences and priorities when treating psychotic disorders because most areas of life are affected. Understanding the impact of participant goals on outcomes is essential as programs design patient-centered treatment plans.

Keywords

Early psychosis; Occupational functioning; Participant preferences; Recovery; Schizophrenia

Introduction

Client-driven advocacy movements and national policy recommendations have inspired mental health care service systems to move toward a patient-centered care approach, which promotes individual agency and choice while emphasizing self-empowerment, self-direction, and mutual respect (Klingaman et al., 2015; Green et al., 2014; Stanghellini et al, 2013; Noiseux & Ricard, 2008; Bellack, 2006). However, the ways in which participants' experiences and perspectives impact outcomes are still not well-understood. It is particularly important to assess participant preferences and priorities for individuals experiencing psychotic disorders because most areas of life are affected (Lenert, Ziegler, Lee, Sommi, &

Mahmoud, 2000). Obtaining participants' values and experiences may help improve intervention effectiveness.

Previous research has shown that recovery-oriented outcomes are a priority for persons receiving mental health treatment (Law and Morrison, 2014). Rosenheck and colleagues (2005) found that individuals who prioritized recovery-oriented activities had fewer positive symptoms, while individuals with greater preference for functional activities, such as work, cared less about reducing symptoms. Additionally, Byrne and Morrison (2014) found that participants prioritized individualized care, collaborative decision making, treatment choice, and confidentiality.

While these research findings raise awareness of the importance of acknowledging participants' priorities, much is still unknown about the ways that participants' preferences may have impacted engagement in treatment and overall recovery. The aim of this study was to explore participant-rated levels of importance in various life domains and whether high priorities had any relevant impact on program outcomes.

Methods

Data

Data were analyzed from the RAISE (Recover After an Initial Schizophrenia Episode) Connection Program (CP), which assessed the effectiveness of an innovative team-based intervention for individuals experiencing a first episode of psychosis (Dixon et al., 2015). The RAISE CP enrolled individuals at two sites, Baltimore, Maryland and Manhattan, New York. Participants were individuals ages 15–35 (16 in New York) who met Structured Clinical Interview for DSM-IV (SCID) criteria for a diagnosis of schizophrenia, schizoaffective disorder, schizophreniform disorder, delusional disorder, or psychosis not otherwise specified, had experienced psychotic symptoms of at least one week's duration with onset within the prior two years, were able to speak and understand English, and were available to participate in the intervention for at least one year (Dixon et al, 2015). The Institutional Review Boards of the New York State Psychiatric Institute and University of Maryland approved study procedures.

Enrollment took place July 2011–February 2013. Of the 65 study participants, 63 provided baseline data on ratings of importance (ROI) and were thus included in this analysis. Research assessments ended June, 2013 and participants were followed for 24 months or until the end of the research project, whichever came first. Thus, most participants did not complete research interviews for the full 24 months (Marino et al, 2015). This study focuses on work/school participation (n=41) and occupational functioning (n=37) after 12 months of participation. This study time point allows insight into initial engagement and the impact of starting this new intervention closely after a first episode of psychosis.

Measures

Demographic data were obtained from participant self-report and included age (mean 22.3±4.2), gender (n=40; 63% male), race, ethnicity, income, educational attainment, and participation in work and school. Due to small sample sizes, we collapsed race/ethnicity to

black, non-Hispanic (n=24; 38%) versus other, and collapsed educational attainment to less than high school completed (n=18; 29%) versus high school or more.

The ROI focused on participants' *Experience of Treatment and Preferences*. The measure was adapted from a scale used in the CATIE Schizophrenia Study (Rosenheck et al., 2005) that focused on measuring and incorporating participant and family preferences in care (Fisher, Shumway, & Owen, 2002). ROI included six questions regarding the relative importance participants attached to different outcomes, such as 1) Increasing energy and interest in activities, 2) Improving social relations, such as doing more social activities with friends and family members, 3) Reducing disturbing and unusual experiences, such as hallucinations and delusions, 4) Reducing confusion and difficulty concentrating resulting in difficulty paying attention or thinking clearly, 5) Reducing medication side effects such as feeling fidgety, restless, or stiff, and 6) Increasing productive activities, such as having a job or going to school, measured on a 5-point scale from 1, not at all to 5, very much.

The Mental Illness Research, Education, and Clinical Center (MIRECC) version of the Global Assessment of Functioning (GAF) scale was used as a primary outcome measure with anchors adapted for individuals with early psychosis (Niv, Cohen, Sullivan, & Young 2007). Unlike the traditional GAF, the MIRECC GAF separates the measurement of social and occupational functioning from the measurement of symptoms. The MIRECC GAF has possible scores ranging from 0 to 100, where scores of 40 are in the dysfunctional range and scores of 70 are in the normal range.

The Positive and Negative Syndrome Scale (PANSS) was used to assess positive, negative, and general symptoms of schizophrenia (Kay, Fiszbein, & Opfer, 1987). Possible scores on each PANSS item range from 1, absent, to 7, extreme.

Analysis

We first compare means of the ROI dimensions, using paired t-tests, to examine which domains were of greatest interest to participants (n=63 at baseline). Following this, we used logistic and linear regression to compare work/school ROI, the ROI ranked most important by participants, to work/school participation (n=41) and occupational functioning after one year of treatment (n=37). SPSS version 23 and Stata version 13.1 were used for the analyses.

Results

Table 1 shows demographic characteristics of participants. Table 2 reports the pairwise correlation coefficients among dimensions of ROI. The strongest importance ratings were placed on increasing productive activities, such as having a job or going to school ($p<0.05$). Rating work/school highly was also associated with rating energy, confusion and side effects highly ($p<0.05$ for all). ROIs for confusion, symptoms, and side effects were also highly correlated ($p<0.01$ for all).

We then examine whether higher participant ratings predict outcome after one year of participation. We focused on the work/school ROI, which is significantly higher than the other domains. We conducted logistic and linear regression analyses, to examine the

association between baseline work/school ROI and work/school participation and occupational MIRECC GAF scores at 12 months (Table 3). Baseline work/school ROI was significantly associated with higher odds of work/school participation at 12 months (OR=4.36; 95% confidence interval (CI) 1.54–12.36]. This association remains significant after controlling for baseline work/school participation, educational attainment, PANSS total symptom scores, age, gender and race/ethnicity (black non-Hispanic vs other). Likewise, a significant association was found between baseline work/school participation and 12-month occupational functioning GAF ($\beta=7.68$ (SE 3.35), $p<0.05$). This remained significant when controlling separately for educational attainment, and approached significance ($p<0.10$) when controlling for baseline occupational functioning GAF and PANSS total symptom scores. However, significance was lost when adding all variables to the model.

Discussion

Study participants' highest priority was placed on increasing productive activities such as having a job or going to school. The divisions of importance ratings are similar to previous findings, which differentiated medically oriented preferences from recovery oriented preferences (Rosenheck et al., 2005; Bellack, 2006; Shumway et al., 2003). The present study's association between work/school and medically oriented preferences may be due to the notion that symptoms, such as energy, confusion and side effects, can hinder the opportunity to obtain work or attend school. Moreover, it should be noted that the demographics of our sample differed from previous studies in this area. Rosenheck and colleagues (2005) studied individuals averaging 40 years in age who had struggled with their illness for an average of 16 years. These individuals' highest priorities involved medically oriented symptoms. These results may indicate that younger populations are more preoccupied with career aspirations, finding a job or completing school.

In the current study, work/school ROI predicted work/school participation, even after controlling for baseline participation, educational attainment, symptoms, and demographic characteristics, and somewhat predicted occupational functioning, after 12 months of participation. This result shows the importance that participants placed on work and school. Previous research has found symptom severity to be weakly connected to factors that predict and influence occupational outcome (Nuechterlein et al, 2008; Brekke and Long, 2000; McGurk and Meltzer, 2000). Overall however, as the association between ROI and work/school participation remains significant in this small sample size, it is an area that should be further explored in future research.

Study limitations should be noted. Participants were limited to six rating domains and did not have the opportunity to come up with their own areas of what was most important to them. In addition, the study sample size was small, and not all participants were followed for the full study duration. Future research should include more participants followed for a longer duration in order to better assess differences as well as to gather more insight into predicting outcomes.

Despite the limitations, this study allows us to examine the association between individuals' values regarding work and school at baseline and subsequent vocational participation, which

has not been studied among persons in early psychosis interventions to our knowledge. Understanding the impact of participant goals on outcomes is essential for designing patient-centered treatment plans.

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TABLE 1Demographic characteristics of RAISE Connection participants reporting Ratings of Importance ($n=63$)

	Mean (SD)	N (%)
Age, years	22.3 (4.2)	--
Gender (male)	--	40 (63%)
Race/Ethnicity		
Black, non-Hispanic	--	24 (38%)
Other	--	39 (62%)
Education		
Less than high school	--	18 (29%)
High school diploma or more	--	45 (71%)
In work or school at baseline		28 (44%)
In work or school at 12 months [†]		34 (83%)
GAF Occupational at baseline	38.6 (18.4)	--
GAF Occupational at 12 months [‡]	64.1 (23.4)	--
ROI_ Work/School at baseline	4.4 (0.9)	--
PANSS Total at baseline	63.8 (14.3)	

[†]n=41;[‡]n=37.

Note demographic variables assessed at baseline

TABLE 2

Correlations of ROI dimensions

	Mean	SD	Energy	Social	Confusion	Symptoms	Side effects
Work/School [±]	4.40	0.94	0.29**	0.16	0.33***	0.13	0.37***
Energy	4.00	1.00		0.24*	0.00	0.02	0.07
Social	3.90	1.09			0.16	0.09	0.12
Confusion	3.52	1.48				0.66***	0.69***
Symptoms	3.41	1.60					0.51***
Side effects	3.19	1.58					

Ratings of Importance (ROI) domains:

Work/School - Increasing productive activities, such as having a job or going to school.

Energy - Increasing energy and interest in activities

Social - Improving social relations, such as doing more social activities with friends and family members

Confusion - Reducing confusion and difficulty concentrating resulting in difficulty paying attention or thinking clearly

Symptoms - Reducing disturbing and unusual experiences, such as hallucinations and delusions

Side Effects - Reducing medication side effects such as feeling fidgety, restless, or stiff

 $p < 0.01$;

**
 $p < 0.05$;

*
 $p < 0.10$;

[±]Mean of work/school ROI significantly higher ($p < 0.05$) than means of other ROIs

TABLE 3
Predictors of Work/School Participation and Occupational GAF after One Year of RAISE Connection Participation

	Participation in Work or School (n=41) OR [95% CI]					Occupational GAF (n=37) β (SE)				
	Model 1	Model 2	Model 3	Model 4	Model 5	Model 1	Model 2	Model 3	Model 4	Model 5
Work/school ROI at baseline	4.36 [1.54–12.36]***	4.47 [1.54–12.93]***	4.33 [1.52–12.32]***	5.91 [1.65–21.12]***	6.30 [1.48–26.80]***	7.68 (3.35)**	6.51 (3.47)*	6.98 (3.27)**	6.65 (3.42)*	5.44 (3.31)
Work/school participation at baseline	--	0.74 [0.09–6.00]	--	--	1.24 [0.07–22.18]	--	--	--	--	--
Occupational GAF at baseline	--	--	--	--	--	--	0.26 (0.22)	--	--	0.04 (0.22)
Education (Less than high school)	--	--	0.51 [0.07–3.98]	--	0.14 [0.003–7.02]	--	--	-14.05 (7.77)*	--	-9.43 (9.42)
Education (High school or more) (ref)	--	--	--	--	--	--	--	--	--	--
PANSS (Total at baseline)	--	--	--	1.06 [0.97–1.17]	1.10 [0.97–1.25]	--	--	--	-0.36 (0.28)	-0.16 (0.27)
Age (years)	--	--	--	--	0.91 [0.56–1.48]	--	--	--	--	0.17 (1.18)
Male	--	--	--	--	1.47 [0.06–38.50]	--	--	--	--	-10.59 (8.34)
Female (ref)	--	--	--	--	--	--	--	--	--	--
Black, non-Hispanic	--	--	--	--	0.15 [0.01–2.20]	--	--	--	--	-16.21** (7.62)
Non-Black (ref)	--	--	--	--	--	--	--	--	--	--

*
 $p < 0.10$;

**
 $p < 0.05$.

 $p < 0.01$;

PANSS = Positive and Negative Syndrome Scale; GAF = Global Assessment of Functioning; Demographic variables assessed at baseline