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Implementing Coordinated Specialty Care for Early Psychosis: The RAISE Connection Program

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Abstract

Introduction—The RAISE Connection Program Implementation and Evaluation study (RAISE-IES) developed tools necessary to implement and disseminate an innovative team-based intervention designed to promote engagement and treatment participation, foster recovery, and

minimize disability among individuals experiencing early psychosis. This paper presents the treatment model and reports on service utilization and outcomes. Using a within-group analysis, it was hypothesized that individuals' symptoms and functioning would improve over time.

Methods—A total of 65 individuals in RAISE Connection Program treatment across two sites, (Baltimore, MD and Manhattan, NY) were enrolled and received services for up to two years. Primary outcomes included social and occupational functioning as well as symptoms. Trajectories for individuals' outcomes over time were examined using linear and quadratic mixed-effects models with repeated measures.

Results—Measures of occupational and social functioning improved significantly over time; symptoms declined, and rates of remission improved. Visits were most frequent during the first 3 months, with a mean of 23.1 ± 11.5 unduplicated staff encounters per quarter, decreasing to 8.8 ± 5.2 such encounters in the final quarter of year 2.

Conclusions—The overall project was successful in that the treatment program was delivered and tools useful to other clinical settings were produced. The strengths of this study lie in the demonstrated feasibility of delivering the coordinated specialty care model and the associated high rates of engagement among individuals who are typically difficult to engage in treatment. Notwithstanding the lack of a built-in comparison group, participant outcomes were promising, with improvements comparable to those seen with other successful interventions.

Introduction

Research has demonstrated that shorter duration of untreated psychosis is associated with better treatment outcomes (1), and that the deleterious effects of psychotic illness on cognitive and social functioning are most dramatic within the first five years after the emergence of psychotic symptoms (2–3). These findings support a conceptualization of schizophrenia as a modifiable illness, with the initial onset of symptoms representing a particularly important time period for the disorder and, therefore, an opportune time for intervention. Researchers world-wide have tested this conceptualization of schizophrenia, examining individual interventions such as low doses of antipsychotic medications (4–5), cognitive and behavioral psychotherapy (6–9), family education and support (10–12), and educational and vocational rehabilitation (13–15). These components have previously been combined into a program of early intervention to promote clinical and functional recovery in international settings and some academic settings in the United States (16–20) but have not yet been tested in routine community mental health centers.

In the United States, this conceptualization has led to a new care model for individuals with first-episode schizophrenia, to foster recovery and prevent disability (21). The NIMH Recovery After an Initial Schizophrenia Episode (RAISE) initiative has funded the development and testing of “Coordinated Specialty Care (CSC)” programs; these are team-based, multi-element interventions that include evidence-based components for the care of individuals experiencing early non-affective psychosis. The RAISE Connection Program is an example of one such CSC program (22).

The Connection Program was a multi-disciplinary and multi-element treatment team that provided a range of treatment components including medication, supported employment/

education, family support and education, psychoeducation, cognitive-behaviorally oriented skills training and support, substance abuse treatment, and suicide prevention. Teams served up to 25 individuals and included a full-time Team Leader, a full-time Individual Placement and Support (IPS) worker, a half-time Recovery Coach and a 20%-time psychiatrist (23).

All aspects of treatment emphasized shared decision-making, recovery, and the view that disability can be minimized by treatment and community support (24). The treatment team had an ongoing focus on maintaining engagement and facilitating treatment participation, providing services in the community when needed. Frequency of contact with participants was designed to be flexible and depended on a participant's stage of treatment, needs, and preferences; there were no 'required' program components. In addition to meetings with participants, treatment teams met together weekly for communication and coordination. The treatment model specified that, on average, participants would receive Connection Program services for up to two years. Program discharge occurred when individuals made a satisfactory transition to other services or, in rare cases, an individual declined further contact. In those cases, individuals were informed that they were welcome to return to care (23).

The RAISE Connection Program was proposed as an 8-site randomized controlled trial comparing the Connection Program intervention to usual care enhanced by a manualized case management approach. After the initial pilot work was completed, the NIMH redirected the work of the contract, requesting that the research continue not as a randomized trial, but as an implementation and impact study to develop and evaluate tools necessary to implement and disseminate a multicomponent intervention for first episode psychosis. The clinical impact of the intervention was still measured, with primary outcome analyses focused on trajectories over time for symptoms and measures of social and occupational functioning. We hypothesized that the RAISE Connection Program intervention would be effective and that, over time, both symptoms and functioning for individuals would improve (as compared to the null hypothesis that they would stay the same over time). In this overview, we present the treatment model, and report on service utilization as well as participants' outcomes on measures of social and occupational functioning and symptoms. Companion papers present information on the state partnerships that brought the work to fruition (25), findings from qualitative interviews with participants (26), and our approach to measuring fidelity and fidelity findings (27).

Methods

Participants

A total of 65 individuals were enrolled in RAISE Connection Program services across two sites, one in Baltimore, MD and one in Manhattan, NY. Community stakeholders helped develop systematically applied strategies to identify participants, including web-based recruitment, outreach to hospitals, clinicians, community agencies, and advertisements. A description of recruitment and outreach strategies used in the study is publicly available in an online manual (28).

Participants were individuals 15–35 years old (16 and older in NY) 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 (NOS) (29). To be eligible for inclusion, individuals must have experienced psychotic symptoms of at least one week’s duration with onset within the prior 2 years, be able to speak and understand English, and be available to participate in the intervention for at least 1 year. Individuals were ineligible if they met any of the following exclusion criteria: non-psychiatric medical condition impairing functioning, psychosis due solely to another condition, mental retardation. All participants (and, for minors, participant’s parent/guardian) provided informed consent; minors provided assent. The Institutional Review Boards of New York State Psychiatric Institute and University of Maryland approved study procedures. The NIMH Data and Safety Monitoring Board provided study oversight. A consort diagram and description of participant flow is provided in an on-line appendix.

Training

Team members received extensive training and supervision in the specific treatment modalities (described above) and in team functioning from national experts who created the intervention and manuals. An initial in-person-training was followed by weekly to biweekly teleconferences supplemented by additional in-person training when needed. Detailed manuals were created for each treatment component and fidelity to intervention components was maintained by ongoing supervision. Manuals for OnTrackNY, the New York extension of the RAISE Connection program, are available online (30–34). The original RAISE Connection manuals are available from the authors upon request.

Procedures

Trained clinical research interviewers completed standardized assessments at baseline, 6, 12, 18, and 24 months or until data collection ended on 6/30/2013. Study recruitment ran from 7/1/2011 through 2/7/2013. Due to a pre-determined study timeline, all research interviews ended 6/30/2013. As a result, participants had research follow-up periods of variable length. Individuals who were enrolled after 2/7/2011 or who declined further participation had shorter follow up periods. The mean length of follow up for research assessments was 546 days \pm 174 (Range 65 to 730). Completion rates for follow up interviews ranged from 75% to 100% and were similar across sites (Table 1). (Note that individuals could continue to receive services even if they refused to participate in research assessments.)

Assessments

An on-line Appendix lists assessments, their timing and baseline values of all measures for the sample. Domains assessed included background and demographic characteristics, social and occupational functioning including participation in work or school, symptoms, diagnosis, neuropsychological functioning, comorbid behaviors, recovery, stigma, medication use and related side effects, as well as individuals’ experience of the treatment model including shared decision making. In order to streamline the recruitment process individuals were evaluated with an abbreviated SCID prior to enrollment, i.e., “eligibility” SCID. A full SCID (27) and the Premorbid Adjustment Scale (35) were completed at 3

months. Primary outcomes included social and occupational functioning, measured with the MIRECC Global Assessment of Functioning (GAF) Occupational and Social Scales (36) with anchors adapted for individuals with early psychosis. Unlike the traditional GAF, the MIRECC GAF separates the measurement of social and occupational functioning from symptoms. For the MIRECC GAF (range 0–100), scores of 40 are in the dysfunctional range, with scores of 70 approaching normal range. We assessed symptoms using the Positive and Negative Syndrome Scale (PANSS)(37). PANSS scores range from 1 (absent) to 7 (extreme). Individuals were considered to be in remission when PANSS items (delusions, conceptual disorganization, hallucinatory behavior, mannerisms and posturing, and unusual thought content) did not exceed 3 (mild). We obtained inter-rater reliability for each primary outcome variable. Cumulative intraclass correlation coefficients (ICC) ranged from 0.71 to 0.95, by site and by rater.

The number and days of hospitalizations were obtained from participant self-report and from study reports of serious adverse events. When two or more psychiatric hospitalizations were separated by medical transfers without discharge between transfers, we considered that to be one event of hospitalization.

Statistical Analysis

In the primary and secondary outcome analyses, we estimated average rate of change over time on primary measures of social and occupational functioning, total symptoms and secondary measures of rate of remission and participation in work or education. In particular, we tested whether primary and secondary outcomes improved over time (as compared to staying the same over time). To test this hypothesis, we used linear mixed effects model with random intercepts and random slopes (continuous measures) or generalized linear mixed effects model (categorical measures) to estimate the overall average rate of change over time from all participants using all available data. Follow up time was defined as time since baseline assessment. We examined both linear and non-linear models (e.g., quadratic models and piece-wise linear models). For primary outcomes, quadratic models did not substantially improve model fit hence we report linear models. Among secondary outcomes, piece-wise linear model with a knot at month six provided better fit for the log-odds of remission than the linear model and thus was used. A linear model provided adequate fit for other secondary outcomes. We computed the effect sizes of primary outcomes as the mean changes over 24 months estimated from linear mixed effects models divided by the standard deviations measured at the baseline (38).

Engagement

For the purpose of this paper, engagement was defined by service utilization. Use of services and treatment visits were aggregated by service quarter. To evaluate engagement quantitatively, we computed each participant's length of time in the study from the date of first clinical visit to either the study end date of 5/31/13 or the date of program discharge. Engagement was the percentage of time that each individual remained on the team roster given the total possible length of treatment or time in study. The numerator was calculated by counting the number of days between the first clinical visit to clinical discharge or end of study. The denominator was the maximum possible length of treatment or maximum

participation in the study. For individuals enrolled after 6/1/11, this was less than two years, while individuals enrolled before that date could have been enrolled for a full two years.

Hospitalization

We report descriptive statistics on hospitalization including sample proportion of participants being hospitalized at least once, total number of hospitalizations, and their median length of stay. We used survival analysis (Kaplan-Meier curve) to analyze time-to-hospitalization to estimate the risk of hospitalization by a given follow-up time (360 days and 720 days) since baseline.

Results

Participant Characteristics

Participants were a mean age of 22.2 ± 4.2 years old, and 41 (63%) were male. Eight participants (12%) were under 18. Almost all ($N=63$, 97%) had never been married. A total of 28(43%) identified themselves as black, 25(39%) as white, 6(9%) as not specified, 4(6%) as Asian/Pacific Islander, 1(2%) as American Indian/Alaskan Native, and 1 (2%) as multi-racial. Sixteen participants (25%) described themselves as Latino or of Hispanic origin. The majority was living with parents ($N=42$, 65%) or other relatives ($N=7$, 11%). Only 2 (3%) individuals were living alone and, similarly, only 2 (3%) were living with a spouse or significant other ($N=2$, 3%). Table 2 provides baseline characteristics for the sample. The baseline rate of education and employment was 43%. Sites maintained fidelity to the model (27) and did not differ statistically in any outcomes.

Engagement

On average, participants met with team members most often during their first 3 months (Table 3). Individuals had a mean of 23.1 ± 11.5 unduplicated staff encounters per quarter, occurring on a mean of 15.1 ± 8.0 different days and decreasing over time to 8.8 ± 5.2 unduplicated staff encounters on 6.3 ± 3.4 days in the final quarter of year 2. Services provided by individual team members followed the same general pattern as overall service utilization. On average, participants received services from the Teams for $91 \pm 21\%$ of the total time that was possible (this was constrained by time of enrollment and study completion). The median time was 100%. Given the differing lengths of possible treatment exposure, only 6/65 (9.2%) of participants received services for less than 50% of the possible time they could be engaged.

Analyses of Primary and Secondary Outcomes Regarding Functioning and Symptoms

The MIRECC GAF Occupational Functioning Scale on average increased by .96 points ($CI=.60-1.32$; $p<.001$) per month in the follow-up period, and the MIRECC GAF Social Functioning Scale increased by .38 points ($CI=.20-.56$; $p<.001$) per month in the follow-up period. On average, the PANSS total score decreased (improved) by .54 points ($CI=-.73- -.35$; $p<.001$) per month in the follow up period. For every month in follow up, on average, the PANSS positive score decreased by .20 points ($CI=-.28- -.12$; $p<.001$), the PANSS negative score decreased by 0.11 points ($CI= -.20 - -.026$; $p=.01$) and the PANSS general score decreased by .22 points ($CI=-.38 - .13$; $p<.001$). The odds of remission increased by 1.55

times (CI=1.31–1.83; $p<.001$) each month in follow up from baseline to month 6. From month 6 to month 24, the odds of remission did not increase over time (odds ratio=1.00, $p=0.94$). For each given participant, the odds of working or being enrolled in school increased by 1.09 times (CI=1.04–1.14, $p<.001$) for each month in follow up. Table 4 shows estimated effect sizes.

Hospitalization

Twenty-four participants (37%, CI=25%-49%) had at least one hospitalization during the study. The total number of psychiatric hospitalizations for these participants was 50, and the median duration of a psychiatric hospitalization was 28 days. Using a Kaplan-Meier analysis, the estimated risk of having a psychiatric hospitalization during the study period was 32% (CI=21% – 45%) by day 360 and 45% (CI=2%-60%) by day 720.

Discussion

The RAISE Connection Program demonstrated the feasibility of implementing a team-based service model, providing a package of interventions previously demonstrated to be effective (39–43) and successfully engaging and retaining individuals with first episode psychosis (FEP) in ongoing care. Participation in RAISE Connection Program services was associated with improved symptomatic and functional outcomes of participants. Further, the 10% rate of disengagement is lower than the 30% rate observed in a recent review of first episode programs (44). Service utilization was highest in the first two quarters, but then stabilized at a modest level over the subsequent 18 months. The large standard deviations reflect wide variation in need.

As hypothesized, the study found improvements in both occupational and social functioning. Notably, MIRECC GAF occupational functioning scores approached normal levels; rates of school and work participation echoed these improvements. This study of the RAISE Connection Program was limited by the absence of a concurrent control condition, so it is difficult to draw inferences about the specific impact of the program relative to an alternative. To mitigate this weakness, we compared our findings to published samples that implemented similar interventions and, in doing so, showed results comparable to other international multicomponent first episode programs. The rate of school and work participation seen with the Connection Program is consistent with other studies that offered supported employment and education services to individuals experiencing early psychosis (42, 45–47). For example, the control arm of a randomized trial of IPS found a rate of employment of approximately 30% (42), a rate well exceeded by our sample. While approximately 40% of individuals in the Connection Program were participating in work or school at study entry, roughly 80% were participating after two years. Another study offered IPS to a cohort of individuals experiencing first episode psychosis, producing elevated rates of school and work participation. IPS was subsequently removed and rates of school and work participation declined to less than 30% in two separate service teams (47). With respect to social functioning, by study end, the MIRECC GAF scores improved to 75 (SE=2.01, CI=71.06–78.96) as estimated from the model, which is slightly above the normal level of a score of 70.

Study hypotheses were also supported with respect to reduction in symptoms. Total PANSS scores as well as each subscale improved over time, including the negative symptom subscale. When compared to other published samples, total PANSS scores were somewhat lower both at baseline and follow up than scores of participants in the EUFEST study; EUFEST participants had baseline PANSS scores in the high 80's while participants in this study had baseline scores in the mid-60's (48). At follow-up, PANSS scores of EUFEST participants dropped to low 50's after one year while RAISE Connection participants were estimated to drop to high 40's after 24 months. Individuals in RAISE Connection Program seemed to have been less symptomatic and more likely to have stabilized prior to enrollment in the program. Though potentially less impaired than other published samples, the RAISE Connection Program participants improved, suggesting the value of ongoing comprehensive care.

Our study found a risk of hospitalization of 32% within a year and about 45% within two years; confidence intervals are wide given the small sample. This rate of hospitalization is consistent with other studies providing specialized early intervention services (49–51), though it is not possible to assess the comparability of these samples. A meta-analysis of predictors of relapse among individuals experiencing a first episode of psychosis who did not necessarily receive specialized first episode services found a pooled prevalence of hospital admissions was 26% (range=12–56%) and 50% (41–52%) at 1- and 2-year follow up (52). Further analyses will be required to understand how RAISE Connection may have impacted hospitalization.

A primary goal of the revised project was to facilitate the future implementation of coordinated specialty care for early psychosis by creating materials useable by other service providers interested in establishing treatment programs for individuals with early psychosis. Materials developed in support of this work include the “Voices of Recovery” video series providing first-person accounts of individuals' experiences with early psychosis symptoms and treatment (<http://practiceinnovations.org/ConsumersandFamilies/ViewAllContent/tabid/232/Default.aspx>); fidelity measures based largely on information programs typically collect as part of routine administrative data (cite fidelity column; redacted for blinding); an interactive tool to help estimate the costs and staffing of treatment teams (53); an outreach and engagement manual; a guide to program implementation (including detailed descriptions of the program, clinic, training and supervision requirements); and treatment manuals. All of these materials are publicly available (<http://practiceinnovations.org/OnTrackUSA/tabid/253/Default.aspx>) and, we hope, will contribute to increasing capacity for effective treatment of early psychosis.

Conclusions

The team-based intervention for individuals with FEP was implemented according to the model and achieved high rates of engagement and participation in treatment, including shared decision-making and family involvement. Client outcomes were promising, showing improvements both in symptoms and functioning comparable to those seen in other successful interventions. Given the lack of a built in comparison group, the primary strengths of this study are the demonstration of the feasibility of implementation of this

program model and the associated high rates of engagement with these difficult-to-engage individuals.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Completion Rates For Research Interviews

Months after Enrollment	Maximum Sample size	Number Completed	% Completed
0	65	65	100%
6	63	57	90%
12	57	44	77%
18	47	36	75%
24	20	15	75%

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Table 2

Baseline Measures of RAISE Connections Participants

Measure		
SCID for DSM-IV Diagnosis (at 3 mo.; N=65)	N	%
Schizophrenia	43	66
Schizoaffective	9	14
Schizophreniform	4	6
Psychosis NOS	3	5
Brief Psychotic Disorder	1	2
No diagnosis Suggesting Eligibility (Psychotic Mood Disorder, Bipolar Type)	2	3
Unknown	3	5
SCID Co-occurring Lifetime Diagnosis (For those with Diagnosis Suggesting Eligibility, n=60)	N	%
Bipolar Disorder NOS	2	3
Depressive Disorder NOS	15	25
Panic Disorder	3	5
Social Phobia	2	3
Obsessive/Compulsive	1	2
Post-traumatic Stress	5	8
Anxiety Disorder NOS	3	5
Alcohol	12	20
Sedative-Hypnotic-Anxiolytic	1	2
Cannabis	22	37
Stimulants	1	2
Opioid	2	3
Cocaine	3	5
Hallucinogenic/PCP	3	5
Employment/Education Status (N=65)	N	%
Neither	37	57
Only Education	13	20
Only Working	9	14
Both	6	9
Clinical and Functional Rating Scales (N=65)	Mean	SD
MIRECC GAF Occupational Functioning Scale (1–100)	38	18.5
MIRECC GAF Social Functioning Scale (1–100)	63.7	12.6
PANSS Positive (7–49)	16.2	6.0
PANSS Negative (7–49)	15.7	5.9
PANSS General (16–112)	32	7.1
PANSS Total (30–210)	64	14.3
Remission (N=65)	N	%

Measure		
In remission (PANSS items < 4: delusions, conceptual disorganization, hallucinatory behavior, mannerisms and posturing, and unusual thought content)	17	26
Previous Hospitalizations in Last Six Months (N=65)	N	%
No previous hospitalization	14	22
One Previous Hospitalization	36	55
Two Previous Hospitalizations	12	1
Three Previous Hospitalizations	3	5
Health Care Coverage (N=65)	N	%
No Coverage	10	15
Unknown	5	8
Currently covered by health insurance	50	77
Covered by Medicare	8	12
Covered by private health insurance plan(s) through Employer	3	5
Covered by private health insurance plan(s) through Cobra	2	3
Covered by private health insurance plan(s) through family member	23	35
Covered by private health insurance plan(s) through other	2	3
Covered by Medicaid	15	23

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Table 3

Participant Service Utilization With Each Team Member By Quarter

Year	Quarter	N	Team Leader Visit		Psychiatrist Visits			IPS Specialist Visits			Recovery Coach Individual Visits			Recovery Coach Group Visits			Total visits			
			M	SD	% with at least one visit	M	SD	% with at least one visit	M	SD	% with at least one visit	M	SD	% with at least one visit	M	SD	% with at least one visit	M	SD	% with at least one visit
1	1	63	8	4.4	98%	7.1	3.7	100%	4.7	4.1	91%	4.9	4.4	94%	1.9	3	56%	23.2	11.5	100%
1	2	60	4.5	3.2	95%	4.1	2.8	95%	2.9	3.1	72%	3.3	3.4	77%	1.7	2.8	40%	4.5	7.5	97%
1	3	53	3	2.8	91%	3	2.4	85%	2.2	2.4	66%	2.3	2.2	70%	1.2	1.9	45%	9.9	6	98%
1	4	50	3.3	3.2	90%	2.7	1.8	90%	2.1	2.3	68%	1.9	1.9	70%	1	1.4	46%	9.9	6.1	98%
2	1	42	2.9	2.9	74%	2.9	2.4	83%	2	2.8	69%	1.8	1.9	64%	0.8	1.2	43%	9	5.8	93%
2	2	32	2.1	2.6	72%	2.8	2.7	84%	2.8	3.9	56%	2.3	2.5	63%	1.1	1.9	34%	9.9	6.9	94%
2	3	21	2.2	2.6	67%	2.8	2.5	86%	2.3	2.3	71%	1.6	2.7	65%	1.1	2.1	33%	8.9	6.5	95%
2	4	6	2.8	2	83%	2	1.8	83%	2.5	2.2	83%	1.7	1.4	83%	0.7	1.2	33%	8.8	5.2	100%

Table 4

Effect sizes of the Impact of RAISE Connection Program on Social Functioning, Occupational Functioning, and Symptom outcomes

Outcome	Mean monthly change ¹	Mean change over 24 months ²	SD	Effect Size
MIRECC GAF Occupational Functioning	0.96	23.04	18.48	1.247
MIRECC GAF Social Functioning	0.38	9.12	12.64	0.722
PANSS Total	-0.54	-12.96	14.26	-0.909
PANSS Positive Symptom Subscale	-0.2	-4.8	6	-0.800
PANSS Negative Symptom Subscale	-0.11	-2.64	5.95	-0.444
PANSS General Subscale	-0.22	-5.28	7.11	-0.743

¹ Mean monthly changes were estimated from linear mixed effects model analyses

² Mean changes over a period of 24 months were estimated from multiplying monthly changes by 24.