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The Impact of a Transitional Intervention for Youth Living with Early Psychosis: A Mixed Methods Study

Original Research

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ABSTRACT

Our research team implemented and evaluated a 12-week manual-based intervention focused on sustaining recovery for youth with psychosis, as they transitioned from Early Psychosis Intervention (EPI) to community-based care teams. The study employed a mixed methods prospective cohort design. Statistically significant improvement in functioning was observed for the intervention group participants only; as well as observed improvements in self-esteem and quality of life (SQLS), compared to the comparison group who demonstrated a significant decline in functioning. The qualitative findings revealed a sense of optimism about the future and the value of realistic goal setting in the intervention group.

KEYWORDS

Early psychosis, transitional intervention, recovery, functioning, goal setting

FUNDING SOURCE

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BACKGROUND

The onset of early psychosis in young adulthood can have lifelong consequences for the individual and their family (Breitborde, 2017; Caseiro, et al., 2012). The term early psychosis indicates that the young person is experiencing psychosis for the first time; an illness where individuals lose contact with reality and experience symptoms such as hallucinations, delusions, and social withdrawal (Badcock & Paulik, 2020). Although early psychosis is a treatable condition, young adults experiencing early psychosis frequently encounter challenges with respect to their educational achievement, occupational or career choices, as well as their sense of self and the formation and quality of personal relationships (Badcock & Paulik, 2020; McCay et al., 2007). Without effective treatment symptoms of psychosis may last for a number of months or even years.

It is now understood that intervention for early psychosis should occur as quickly as possible in order to promote optimal recovery. Early Psychosis Intervention (EPI) programs offer a range of medical and psychosocial treatment modalities, often including case management, psychoeducation and

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medication management predominantly in community settings (Dixon et al., 2015; Murphy & Brewer, 2011). Considerable evidence exists to support the effectiveness of EPI in treating the onset and early phase of psychotic illness; creating opportunities for recovery and improving quality of life overall (Correll, et al., 2018; Henry et al., 2010; Jordan et al., 2018; Malla et al., 2017; Marino et al., 2015; McCay, et al., 2019; Penno, Hamilton & Petrakis, 2017; Verma, Poon, Lee, Rao & Chong, 2012). Specifically, outcome studies evaluating the effectiveness of EPI programs, which typically range in length from two to five years, have documented significant improvements in symptoms, as well as occupational and social functioning (Marino et al., 2015; Verma et al., 2012). Researchers have also documented that subjective quality of life (Marino et al., 2015; Turner, Boden, Smith-Hamel & Mulder, 2009) has improved following treatment in EPI programs, as well as the quality of social relationships (Penno, Hamilton & Petrakis), offering further evidence that EPI impacts not only symptoms but multiple dimensions of recovery.

Consistent with these research findings, our research team (as part of a study to assess the effectiveness of a transitional intervention for youth living with early psychosis) found that participants achieved optimal outcomes at the time they were identified as ready for discharge from three EPI programs in two Canadian provinces (Ontario and Nova Scotia) (McCay, 2019). Specifically, these youth had decreased symptomatology and psychological distress, as well as increased quality of life and overall functioning following EPI treatment. Ultimately, our research team was interested in understanding how the benefits attained in EPI programs could be sustained once youth had been discharged. Research findings suggest that although dramatic improvements have been observed across a number of dimensions for young people who receive EPI treatment, there is a substantial risk that many of these gains may be lost following discharge (Bertelsen et al., 2008; Gafoor et al., 2010; Kam, Singh & Upthegrove, 2015; Lester, et al., 2012; Secher, et al., 2014; Singh, 2010). A particular concern identified in the literature pertaining to the trajectory of youth following treatment in EPI is the risk of relapse (Kam, Singh, & Upthegrove, 2015; Taylor, Pena, Perez-Iglesias, 2018). The risk of relapse is greatest in the first year following discharge and targeted interventions are recommended to address functional recovery in order to maintain the gains made in EPI (Kam et al.). It is evident that notwithstanding the effectiveness of EPI programs in meeting the needs of youth during the early phase of the illness, the question of how to best support recovery during and following the transition from EPI services to full engagement in the community is an urgent clinical and research priority.

One approach to meeting the needs of youth following discharge from EPI has been to extend EPI beyond two years; adding an additional three years of care in a modified service delivery model (Albert et al., 2017; Norman et al., 2011; Malla, et al., 2017). One such study undertaken at the Prevention and Early Intervention Program (PEPP) in London Ontario created a less intensive three-year intervention, which followed the usual two-year PEPP program to support ongoing recovery within an EPI environment (Norman, et al.). The study results indicated that the less intensive follow-up did support the gains acquired through EPI specifically pertaining to positive symptoms and recovery (Norman et al.). Similar results were also obtained by Malla et al., where participants who participated in an extended five-year EPI were found to have a significantly longer period of remission of positive and negative symptoms compared to those who received two-year EPI plus regular care. On the other hand, a study by Albert et al. (2017) found few beneficial effects of a longer five-year EPI program compared with two years of EPI and treatment as usual, but the authors suggest that this finding may be due to the high level of treatment provided to the two-year comparison group. Although there are somewhat mixed results associated with extended EPI programs, the potential benefits support exploring this strategy. However, it is not always possible for EPI programs to offer continued services, even with a modified service delivery, over the course of five years. Further, the question of how best to maintain the positive outcomes acquired through EPI once the young person living with early psychosis is discharged and care is transferred to community-based services remains a significant concern and largely unanswered question. In an effort to contribute to addressing this knowledge practice gap, our research team developed ***an innovative multi-component, evidence-based intervention to sustain the recovery process for youth experiencing psychosis as they transitioned from EPI specialized services to community-based care***.

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METHODS

Our research team implemented and evaluated a 12-week manual-based transitional intervention to assess the effectiveness of the intervention in sustaining the recovery process for youth with psychosis as they transitioned from specialized services to community-based care. This intervention included a 4-week group and individual component focused on discharge readiness, followed by an 8-week individual component focused on community-based care. A Transition Coach from each site (Toronto, Ottawa and Halifax) who was a mental health professional trained in the transitional intervention, delivered the intervention components, which were designed to support youth as they transitioned from their EPI program to community-based care. Specifically, we hypothesized that participants receiving the 12-week transitional intervention would sustain optimal levels of recovery at mid-intervention (i.e., immediately following the 4-week discharge readiness component) and immediate post-intervention (i.e., immediately following the 8-week community-based care component) on indicators of self-esteem, engulfment, hope, quality of life and functioning, compared with participants receiving only usual treatment. In addition, we hypothesized that these indicators would be maintained at four weeks post-intervention. Although the intervention was not hypothesized to influence mental health symptoms, we monitored symptom levels and substance use in order to ensure that the intervention did not have any negative effect on mental health symptoms.

Study Design

The study employed a mixed methods prospective cohort design using both quantitative and qualitative methods. This design enabled the procurement of similar, yet distinct comparison and intervention groups recruited from each of the three EPI program settings (Toronto, Ottawa and Halifax). The comparison cohort was obtained by recruiting participants who were identified by the EPI team as being ready for discharge within two months and who were receiving usual treatment. This cohort was recruited prior to the introduction of the evidence-based transitional intervention and, as such, comparison cohort participants were not exposed to the study intervention. Once a Transition Coach from each of the three EPI program settings was trained in the transitional intervention, participants who were identified as being ready for discharge within two months were invited to participate in the intervention in addition to receiving usual care.

Data were obtained from participants in the comparison and intervention groups at approximately the same four time points: baseline (Time 1), mid-intervention (Time 2; 4 to 8 weeks post-baseline), immediate post-intervention (Time 3; 12 to 16 weeks post-baseline), and four weeks later (Time 4; 16 to 20 weeks post-baseline). Data collected at mid-intervention (i.e., following the 4-week discharge readiness component) were collected anywhere from 4 to 8 weeks post-baseline in order to allow adequate time to recruit a sufficient number of participants for the 4-week discharge readiness component and to ensure that these data were collected prior to the start of the 8-week community-based care component. As such, subsequent data collection time points were adjusted accordingly. Within-group comparisons at mid-intervention and immediate post-intervention determined the effects of the intervention. Within-group comparisons were conducted at Time 4 to assess the sustainability of treatment effects. Additionally, one-to-one semi-structured interviews were conducted with participants who completed the transitional intervention based upon interest and availability.

Recruitment

Participants were recruited across sites between November 2015 and February 2019. To be eligible to participate in the comparison and intervention groups, individuals must have been: 1) receiving care in one of the three EPI program settings; 2) identified by the EPI team as being ready for discharge from the program within two months; 3) 18-35 years of age; 4) able to speak and understand English; and 5) able to provide informed consent. The diagnosis of individuals receiving care in these programs falls within the schizophrenia spectrum or is otherwise defined as a primary psychotic disorder. For both the comparison and intervention groups, eligible individuals were invited to participate by a healthcare provider within their program. The Research Ethics Boards at Ryerson University and at each EPI program site approved the study.

Sample

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A total of 65 individuals were recruited to participate in the study: 38 were recruited for the comparison group and 27 for the intervention group. Of the 38 comparison cohort participants, 30 participated in follow-up research interviews while eight dropped out (i.e., completing only the baseline questionnaires). Of the 27 intervention cohort participants, 17 completed both the 4-week discharge readiness component and the 8-week community-based care component of the intervention, five completed only the 4-week discharge readiness component, and five dropped out of the intervention (i.e., completing only the baseline questionnaires). These dropout rates are comparable to other intervention studies in early psychosis populations.

12-week Transitional Intervention

Three occupational therapists, one from each EPI program setting (Toronto, Ottawa and Halifax), were employed as Transition Coaches for the current study and delivered the Transitional Intervention to study participants. Each Transition Coach received one-to-one training in the manualized 12-week intervention. Ongoing support and consultation continued throughout the intervention, both on a one-to-one basis and in a group format as needed via teleconference.

As previously stated, the 12-week transitional intervention included both a 4-week group and an individual component focused on discharge readiness, followed by an 8-week individual component focused on community-based care. The 4-week group component involved weekly group meetings led by the Transition Coach. Weekly discussion themes included the following: Week 1 - Getting to know the youth; exploring hopes, dreams and goals; Week 2 - Exploring barriers; minimizing self-stigma and engulfment; self-care; Week 3 - Positive relationships and interpersonal effectiveness skills; and Week 4 - Working toward meaningful life goals. Additionally, five concrete skills, adapted from dialectical behaviour therapy (DBT) (Linehan, 2015), were taught over the course of the group to encourage and facilitate self-care, as well as the formation and maintenance of positive relationships.

Delivered concurrently with the 4-week group component, the 4-week individual component focused on discharge readiness involved weekly one-to-one sessions with the Transition Coach. During these individual sessions, the Transition Coach used an approach informed by motivational interviewing (MI) and cognitive behavioural principles to invite youth to identify and work toward self-identified goals. As an outcome of these individual sessions, the youth also developed their 'personal passport', which was a tangible tool to help them reaffirm their sense of self by identifying hopes, goals, accomplishments and problem-solving plans.

During the second phase of the intervention, namely the 8-week individual component focused on community-based care, the youth and the Transition Coach continued to work on the youth's goals, establishing a concrete planning, implementation and evaluation cycle. These MI-informed individual sessions aimed to help the youth build motivation to stay engaged with goal-setting processes, and to be active and collaborative participants in their own healthcare experiences. As part of this second phase of the intervention, the Transition Coach was also available to accompany the youth to community appointments (e.g., healthcare, recreational, or vocational appointments).

The Transition Coaches were asked to complete integrity checklists created by the research team for each weekly group and individual session of the manualized 12-week transitional intervention. For each session held, the Transition Coaches were asked to rate themselves in terms of whether the intervention was delivered as intended, which also served to reinforce the substantive content of the intervention for the Transition Coaches. These ratings indicated that the Transition Coaches were able to address all of the components of the intervention.

Quantitative Measures

Sociodemographic data were collected regarding individual characteristics such as age, time of illness onset, gender, sexual orientation and living arrangements. All participants were asked to complete a number of standardized measures with sound psychometric properties to assess self-esteem, engulfment, hope, quality of life and functioning. Furthermore, symptom levels and substance use were monitored with well validated instruments.

The Rosenberg Self-Esteem Scale (RSES) (Rosenberg, 1979) is a 10-item self-report inventory

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developed to measure global self-worth. The Modified Engulfment Scale (MES) (McCay, 1998) measures the degree to which illness defines an individual's self-concept and has been used with youth recovering from early psychosis. The Miller Hope Scale (MHS) (Miller & Powers, 1988) is a 40-item Likert self-report scale measuring multi-dimensional attributes of hope. The Schizophrenia Quality of Life Scale (SQLS) (Wilkinson et al., 2000) is a 30-item self-report questionnaire, comprising three scales (psychosocial, motivation and energy, and symptoms and side-effects). Each scale has a range from 0 (best possible health) to 100 (worst possible health), with lower scores indicating greater quality of life. The Global Assessment of Functioning Scale (GAF) (Endicott, Spitzer, Fleiss & Cohen, 1976) was used to rate social, occupational and psychological functioning. The Social and Occupational Functioning Assessment Scale (SOFAS) (Goldman, Skodol & Lave, 1992) assesses social and occupational functioning exclusive of psychiatric symptoms.

In order to monitor symptom levels and substance use, participants completed the Symptom Checklist-90-Revised (SCL-90-R) (Derogatis, 1994); to derive the Global Severity Index (GSI); providing an overall measure of psychological distress and is considered to be the best single scale indicator of symptomatology. The CES-D (Radloff, 1977) is a 20-item scale measuring depression. The Depressive Symptom Index – Suicidality Subscale (DSI-SS) (Joiner, Pfaff & Acres, 2002) is a 4-item self-report questionnaire to identify the intensity of suicidal ideation and impulses over the past two weeks. Finally, the Adolescent Version of the Michigan Alcoholism Screening Test (MAST) (Snow, Thurber & Hodgson, 2002), a 19-item self-report inventory, was used to assess alcohol and drug use in adolescents.

Quantitative data analysis

Missing data accounted for less than 5% of data points and therefore item mean substitution and scale mean substitution were used to address missing data. The assumption of normality was assessed prior to commencing statistical analysis and all data were approximately normally distributed. In order to describe the sample, the frequencies, means and standard deviations for all study variables were calculated. To compare the sociodemographic characteristics and study measures for the intervention and comparison groups at baseline, independent t-tests were conducted for continuous variables and chi-square tests were conducted for categorical data. To compare the sociodemographic characteristics and study measures for each group at baseline between the three study sites, a one-way ANOVA was conducted for continuous variables and chi-square tests were conducted for categorical data. A series of paired t-tests was conducted to assess for change between T1 and T2, and T1 and T3 on all study measures for the intervention and comparison groups. In addition, paired t-tests were conducted on all study measures between T3 and T4 to assess the sustainability of outcome variables overtime. The significance level was set at $p = .05$.

Qualitative data analysis

In addition to completing standardized quantitative measures, one-to-one semi-structured interviews were conducted with participants who completed the intervention. These interviews were designed to gain an understanding of their experiences in the intervention, the impact of the intervention, and suggestions for improvement. Fifteen participants were interviewed using a standard set of questions. Interviews ranged from 30-60 minutes. Of the 15 interviews, 12 were audio recorded and transcribed verbatim. For those participants who declined to be recorded, handwritten notes were taken. The principal investigator and experienced research staff carried out the primary thematic analysis and coding. The thematic analysis followed Miles and Huberman's (1994) stages of analysis. The transcripts were read and re-read to elicit meaning units. The meaning units were then analyzed and organized into themes; resulting in the coding structure that described the experiences of youth in the intervention. Reliability of the coding structure was established by having transcripts read by other members of the research team for consistency. Differences in coding were resolved through consensus.

RESULTS

Quantitative Findings

Table 1 provides an overview of the sociodemographic characteristics for this sample (N = 65) at baseline. The mean age of participants was 26.65 years old (SD = 4.11). Participants had been residing in Canada for a mean of 23.85 years (SD =

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6.55) and had attained a mean of 13.05 years (SD = 2.00) of education. Furthermore, participants had been living with their diagnosis for a mean of 5.15 years (SD = 2.75). The sample was made up of a greater number of males (72.3%) than females (26.2%), with the majority identifying their sexual orientation as heterosexual (93.8%) and their relationship status as single (92.3%). The majority of participants lived either with their parents (49.2%) or in their own place (36.9%). Most were not in school (87.7%), were unemployed (56.9%), and identified that their illness had impacted their participation in school (64.1%) and their employment (62.3%). The vast majority stated they took their medications regularly (84.4%) and accessed social/community services (69.2%). At the time of the final data collection point (T4), the majority of participants had transitioned to community-based care.

At baseline, there were no significant differences in sociodemographic characteristics between the intervention and comparison groups. Furthermore, for both groups at baseline, there were no significant differences in sociodemographic characteristics between the study sites.

There were no statistically significant differences between sites on any of the study measures for either group at baseline. As such, the outcome data from all three sites are reported together. Baseline outcome measures for the intervention and comparison groups are reported in Table 2. A series of independent t-tests revealed no statistical differences between the intervention and comparison groups at baseline. As previously stated, although the intervention was not hypothesized to influence mental health symptoms, we monitored symptom levels and substance use in order to ensure that the intervention did not have any negative effect on mental health symptoms. At baseline, there were no significant differences in global symptoms, depression or suicidality between the intervention and comparison groups. However, a significant difference was detected with respect to substance use (MAST) (t = 2.131, df = 63, p = .039), with the intervention group having higher mean substance use scores (5.89) (SD = 5.61) than the comparison group (3.24) (SD = 3.82) at baseline.

A series of paired t-tests was conducted to assess for change between T1 and T2 (Table 3), and T1 and T3 (Table 4) on all study measures for the intervention and comparison groups. From baseline (T1) to mid-intervention (T2), no statistically significant differences were found for either group. From baseline (T1) to immediate post-intervention (T3), however, statistically significant improvement in functioning was observed for the intervention group participants only; specifically, global functioning (GAF) (t = -2.632, df = 16, p = 0.018), and social and occupational functioning (SOFAS) (t = -2.331, df = 16, p = .033). Furthermore, observed improvements in self-esteem (RSES) (t = -1.923, df = 16, p = .072) and quality of life (SQLS), specifically, motivation and energy (t = 1.938, df = 16, p = .070), approached statistical significance. In contrast, participants in the comparison group demonstrated a significant decline in social and occupational functioning (SOFAS) (t = 2.085, df = 22, p = .049) from T1 to T3.

In addition, there were no significant differences in symptom levels or substance use in either the intervention group or comparison group from T1 to T2. Furthermore, both the intervention group (t = 2.742, df = 16, p = 0.14) and the comparison group (t = 2.522, df = 22, p = 0.19) demonstrated a significant improvement in substance use (MAST) from T1 to T3. Taken together, these findings pertaining to mental health symptoms indicate that the intervention did not have a negative effect on symptom levels.

In order to assess the sustainability of outcome measures over time, paired t-tests were conducted on all study variables between Time 3 and Time 4 (Table 5) for each group. Not only did these tests indicate that all of the gains attained during the transitional intervention were sustained at 4 weeks post-intervention but observed improvements in self-esteem (RSES) (t = -2.092, df = 14, p = .055) approached statistical significance for the intervention group participants only.

Qualitative Findings

Although a number of themes were identified in the data, those that best capture the youth's experience of participating in the intervention are reported here. These themes include: Welcoming support in the midst of experiencing fear and loss; Experiencing the transitional intervention, and Impact of the transitional intervention.

Welcoming Support in the Midst of Experiencing Fear and Loss. This first major theme reflects the insecurity experienced by youth as they transitioned

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from the EPI program to the community. The time leading up to discharge was associated with apprehension as youth prepared to leave the certainty of the EPI program for the uncertainty that lay ahead. Three sub-themes emerged within this major theme: a) *experiencing apprehension*; b) *preparing to let go of the EPI program*; and c) *welcoming support: choosing to take part in the transitional intervention*.

In the first sub-theme, *experiencing apprehension*, youth shared their concerns regarding an uncertain future:

I was scared, cause I thought I wouldn't have my medication anymore and I didn't know what was gonna happen, so yes I did have concerns for the future. (125)

Um well it was like I was going through a pretty hard time because I was really scared about my future and I was really nervous about it and I felt like I would never get anywhere in life... (14)

Many had come to know the EPI program staff well and expressed uncertainty regarding whether community agencies would provide effective support in the same way as the EPI program. One participant expressed her concern about being perceived as a low priority for continued care, given her improved health status:

I was just wondering if I was going to get the same kind of help that I was receiving. But it seems like I'm a low priority because…my state was ok, my sleep was ok. (15)

In the second sub-theme, preparing to let go of the EPI program, youth talked about how they benefitted from the care they received and expressed a desire to continue working with the team, even as they knew they were about to be discharged. As one young person observed:

No, I just wish I didn't have to be discharged in total. Because, I wanted to work with my doctor a little bit longer on things. (124)

EPI Programs were an anchor for youth because of the access to an experienced team that understood them and their illness experience. Many youth had established strong trusting relationships with staff and realized the benefits of care they received. One young person described this in the following way:

I really enjoyed 'EPI program' cause I felt like it was a really good community and I felt like everyone was really um kind, and like compassionate and empathetic. (14)

The third sub-theme, welcoming support: choosing to take part in the transitional intervention, reflects the youth's decision to participate in the transitional intervention. For youth, the intervention offered the possibility of working on goals and was an opportunity to focus on what they valued. In the following quote, one participant indicated he could benefit from help with goals:

I was hopeful that it could help me with my goals, and I was interested in seeing if it could actually motivate me or inspire me to work toward my goals and to be successful in them. (119)

The intervention was thus seen as providing additional support as youth transitioned out of the EPI Program.

Experiencing the Transitional Intervention. The second major theme reflects youth's experience of participating in the various components of the transitional intervention, namely: a) *being in a group: realizing that I am not alone*; b) *working with a Transition Coach*; and c) *working towards my goals.*

The first sub-theme reflects youth's perception of participating in the group component of the intervention. The group was perceived as valuable, since participants realized they were not alone and that others had challenges too; as these participants aptly described:

It was helpful because the other guy there and I really related because he went through a lot of the stuff I went through and stuff like that. He was nice and pretty open during the meetings, so it seemed like we went through a lot of the same stuff. (118)

[It was] encouraging to see others with the same illness [and] share lots of things in common. (215)

The group was an opportunity to share experiences, as captured by another participant:

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It was helpful to have the structure in the groups, but it was also helpful not to follow it too intensely, and to be able to focus on what we wanted to, so that we could listen and relate to each other. (119)

In the second sub-theme, working with a Transition Coach, youth described the experience of working with a coach as a process that was validating, action-oriented, and built trust. Within the context of this strong relationship with the coach, youth felt heard as demonstrated in the quote below:

Well she gave me time to talk about things ya know. To be open with her about my troubles and concerns. That helped. (18)

The relationship with the Transition Coach centred on the youth's needs and their support through the transition. Youth felt they benefitted from this support, as expressed so clearly in the following quote:

[The transition coach] helped me a lot with that. She helped me with meeting [new staff] to see who she was. She didn't just say 'go there' and drop me just like that. She didn't say 'this is who you're going to meet' she actually went with me to meet them which was very helpful. (118)

The Transition Coach worked with youth using a person-centred approach, which was encouraging and geared to helping youth experience success. One participant described his experience in this way:

I liked the involvement – it was way more involved than I thought it would be. It focused on what would make me happy and feel successful. Meeting at an art studio and doing things that are related to my goals was great. (119)

[She] made me realize that I wasn't giving myself credit for the things that I did. (213)

The third sub-theme, working towards my goals, reflects the experience of participants as they worked toward goals that were meaningful to them, such as; improving relationships, returning to school, and dealing with drug and alcohol use. The Transition Coach also provided guidance that was specific, concrete and tailored to the youth's self-identified goals. Youth, as exemplified in the quote below, learned a range of skills in goal-setting:

Well [the Transition Coach] and I would talk about how to reach those goals and we would write them down and kind of set them in place and like was strategic like steps and also like kind of break them down like how we would do it…And she helped me kind of consider like what goals are optimal for me at this time in my life. (14)

In the following quote one young person described working on a resume with the Transition Coach, which he hoped would result in employment:

Um, probably when I got a new resume, she helped me build a new resume and I got it on my email now and that's gonna help me get a job, so. That's probably the most helpful thing. (121)

Impact of the Transitional Intervention. Easing the Transition. The third major theme, impact of the transitional intervention: easing the transition, captured the benefits of participating in the transitional intervention from the youth's perspective and included: a) *reclaiming a valued sense of self and increasing self-reliance* and b) *envisioning future possibilities*.

In the first sub-theme, *reclaiming a valued sense of self and increasing self-reliance*, a valued sense of self contributed to a sense of agency that helped diminish the engulfing elements of the illness. The change that characterized the transition was expressed by the following participant in this way:

…just cause I have schizophrenia doesn't mean it can hold me back from having a good future…Like…(I) feel hopeful for the future like a lot of people (I) know go through schizophrenia and hallucinations but they're still capable, have the same potential as everybody else. (17)

Just trying to be a better version of [my] self. 213

Youth expressed an enhanced confidence which seemed connected to success in planning and meeting even modest goals that they themselves established. A number of youth talked about feeling proud of accomplishing self-set goals, as captured in the following quote:

The study [intervention] taught me to really set time frames for my goals instead of just saying 'someday',

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and to hold myself accountable for the goals I have. Now I'm just trying to keep that up. This study really helped by holding my hand through this process and now I feel confident in self-sufficiency and can hold my own hand. (119)

As youth gained a renewed sense of confidence and increasing self-reliance, they began to re-evaluate previously held beliefs and an increased sense of possibility was evident.

The second sub-theme, *envisioning future possibilities*, reflects this stage in the transition. A sense of possibility was described as rooted in hope for a better future and the ability to achieve goals that were important to the youth, regardless of how small. Youth were beginning to plan their lives despite challenges. One young person described his experience in this way:

Um I feel more secure about my future like more confident in my … Um and I, I like I kind of I'm able to um work towards certain things better. Now it's like easier for me to do like the things that I need to do during the day. (14)

Participants could situate their illness experience within a broader context; seeing themselves as persons and overcoming the challenges and perceived negative expectations associated with their illness. There was an emerging sense of hope and possibility that many had not experienced in some time. This sense of hope is captured in the following quote:

Yeah, previously I was thinking that like even if I like go to school and get a degree and get a job that I want to do I'll always be second tier to you know someone that doesn't have the problems that I have. And that I wouldn't be you know a totally functional member of society ever…And that opinion of myself has changed especially recently… I'm starting to become the person that I remember being before … and it feels amazing. (20)

These qualitative descriptions suggest a sense of optimism about the future and the value of realistic goal setting. Many components of the transitional intervention enabled youth to focus on their life and what they wanted to do. The role of the Transition Coach, however, was pivotal in working with youth in a person-centred way to navigate the time of transition.

DISCUSSION

The qualitative findings of this mixed methods study conveyed an understanding of the apprehension experienced by the intervention participants, as they approached discharge from EPI programs and were dealing with the transition to community-based care. The apprehension centered on not knowing what to expect, as well as on an underlying sense that life would be difficult without the possibility of achieving hoped for goals and aspirations. There was also a sense of loss regarding trusting relationships with healthcare practitioners who had provided valuable support through the recovery process. The level of uncertainty experienced by participants within the context of leaving EPI programs was a catalyst for youth to participate in the transitional intervention. Importantly, youth viewed the intervention as an opportunity to work toward achieving their goals.

Youth in the intervention and comparison groups had achieved optimal outcomes at the time they were identified as ready for discharge from their EPI programs. For those participating in the transitional intervention, these optimal outcomes were sustained over the 20-week follow-up across a number of dimensions including functional levels, self-esteem, engulfment, hope and quality of life. Participants who did not have the benefit of the transitional intervention also demonstrated comparable levels of recovery across some of the same study variables, specifically; self-esteem, engulfment, hope and quality of life. Taken together, these findings are consistent with the literature, which documents the positive impact of early intervention services on recovery including a sense of hope for the future (Lester, et al., 2012), managing the impact of negative stereotypes on self-esteem (McCay, 2007; Romm et al., 2011), and quality of life (Browne, et al., 2017; Fujino et al., 2016).

On the other hand, indicators of social, occupational and psychological functioning revealed differing results across the intervention and comparison groups. Specifically, participants in the intervention group demonstrated statistically significant improvements on social, occupational and psychological functioning, as measured by the GAF and SOFAS; gains, which were maintained at 20 weeks

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post-baseline. Participants in the comparison group, however, who did not have the benefit of the transitional intervention, demonstrated a significant decline in functional levels as measured by the SOFAS, a decline that persisted at 20 weeks post-baseline. A substantial interest has been placed in the literature on the level of functioning attained following EPI programs with authors (Verma, et al., 2012; Verma, Subramaniam, Abdin, Poon & Chong, 2012) identifying the cutoff score of 61 or greater on the GAF as indicative of functional recovery. It is noteworthy that in the current study the mean GAF score at immediate post-intervention and at 20 weeks post-baseline for the intervention group was 73.2; suggesting that intervention participants had attained increased levels of functioning, which exceeded those levels generally reported in the literature for this population (Norman et al., 2011). It is possible that the unique elements of the manualized transitional intervention, specifically the use of an evidence-based approach to goal-setting in the context of a supportive relationship with the Transition Coach, could account for these positive results.

Further, as noted, participants in the comparison group who did not have the benefit of the transitional intervention demonstrated a significant decline in functional levels as measured by the SOFAS. It is important to note that the comparison group scores on the SOFAS were higher than scores reported for young adults completing an EPI program (Klaas et al., 2017), suggesting a reasonable level of social and occupational functioning in the comparison group. However, what is concerning is the downward trend of these scores with respect to the level of functioning for those who did not receive the transitional intervention.

In addition to the quantitative measures, which indicated significantly improved levels of functioning, youth who participated in the intervention also subjectively described improved functioning. Specifically, they exemplified how engaging with the Transition Coach within the context of the intervention enabled them to focus on setting and achieving goals that were important to them, such as returning to school and pursuing work opportunities. The youth also emphasized the importance of the relationship with the Transition Coach, which was experienced as person-centered, supportive and flexible; with the Transition Coach supporting youth to tailor their personal goals to best meet their needs.

It was also clear from the youths' descriptions that working toward their goals had a positive impact on their sense of confidence and self-reliance. This finding aligns with the increased self-esteem scores attained following both the completion of the transitional intervention and at 20 weeks post-baseline, as well as the trend observed in the motivation and energy subscale of the SQLS toward improved motivation.

It is also noteworthy that participants described an improved sense of self, which was clearly linked to both achieving goals and to challenging negative expectations held by themselves and others pertaining to living with a mental illness. Participants also identified the value of sharing experiences with other youth in the group setting, which likely helped to challenge negative expectations regarding themselves and the illness. Group programs are well recognized as effective strategies for promoting social functioning (Cotton et al., 2011), as well as enhancing sense of self and reducing the engulfing effects of the illness (McCay, 2007). Although there was not a statistically significant decrease in engulfment or increase in hope scores in the current study, participants in both the intervention and comparison groups demonstrated MES and MHS scores comparable to those who had completed a 12-week intervention to reduce self-stigma and engulfment (McCay, 2007), suggesting that the participants in the current study had attained relatively positive levels of these outcomes.

It is possible that the qualitative findings pertaining to participants' perceptions of an improved sense of themselves was linked to participating in setting future-oriented goals. Furthermore, participation in the transitional intervention seemed to allow youth participants to gain increased confidence in their capacity to achieve goals and to live a "normal" life. By way of contrast, there was a sense expressed by some youth that, prior to the transitional intervention, it would not be possible to achieve hoped for goals and aspirations. There was also a sense of loss regarding trusting relationships with healthcare providers. Following the transitional intervention, a sense of hope for a better future had been rekindled in spite of the illness and there was an increased sense of security in themselves, apart from their relationships with healthcare providers.

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The current study has several limitations. Foremost, the study sample is relatively small. Furthermore, the study recruited only participants who were interested and able to participate in a 12-week face-face intervention; thus, limiting generalizability. Moreover, the duration of the study intervention and follow-up was over a period of five months and although the majority of participants had transitioned to community-based care at the 20 weeks post-baseline, it is not possible to know whether the benefits observed in this preliminary study would be sustained over the longer term.

There are increasing efforts to develop accessible interventions which may support youth to continue to engage in recovery and to maintain gains achieved in EPI programs. For example, the HORYZONS trial currently underway offers an on-line intervention with a focus on social functioning (Alvarez-Jimenez et al., 2019). There is no doubt that innovative and accessible approaches to providing ongoing support for youth to continue to engage in recovery following the completion of EPI are urgently needed.

CONCLUSION

The findings from the current study offer promise that a transitional intervention, such as the one we used, has the potential to extend the benefits of EPI programs through ongoing relationship building, group interaction and meaningful goal-setting; reinforcing for youth their potential to engage in a life that they had previously envisioned for themselves prior to their illness. This transitional intervention appears to be particularly effective in supporting the ongoing development of psychological, occupational and social functioning, all of which are critically important in the context of meaningful recovery. Overall, the results attained in this study suggest that the introduction of an active intervention to support the process of transition to community-based care may indeed enable youth to continue to engage in recovery and to maintain the gains achieved in EPI programs.

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Table 1: Sociodemographic Characteristics of Sample (N = 65)

Demographic variables	Intervention (N = 27)		Comparison (N = 38)		Total Sample (N = 65)	
	Mean	SD	Mean	SD	Mean	SD
1. Age	26.00	4.50	27.11	3.80	26.65	4.11
2. Length of time since diagnosis (years)	4.50	2.00	**5.64	**3.14	**5.15	**2.75
3. Length of time in Canada (years)	23.24	5.88	24.29	7.04	23.85	6.55
4. Years of education (grade 1 and up)	13.52	1.95	12.71	2.00	13.05	2.00
	N	%	N	%	N	%
5. Study site						
Toronto	9	33.3	11	28.9	20	30.8
Ottawa	10	37.0	9	23.7	19	29.2
Halifax	8	29.6	18	47.4	26	40.0
6. Gender						
Male	20	74.1	27	71.1	47	72.3
Female	7	25.9	10	26. 3	17	26.2
Other	0	0	1	2.6	1	1.5
7. Current living situation						
Parent's home	15	55.6	17	44.7	32	49.2
Own place	9	33.3	15	39.5	24	36.9
Other	3	11.1	6	15.8	9	13.8
8. Sexual orientation*						
Heterosexual	26	96.3	34	91.9	60	93.8
*Other****	1	3.7	3	8.1	4	6.3
9. Relationship status						
Single	24	88.9	36	94.7	60	92.3
Other	3	11.1	2	5.3	5	7.7
10. Medications*						
Yes	23	88.5	31	81.6	54	84.4
No	2	7.7	5	13.2	7	10.9
Sometimes	1	3.8	2	5.3	3	4.7
11. School						
Yes	5	18.5	3	7.9	8	12.3

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No	22	81.5	35	92.1	57	87.7
12. Illness impact on school*						
Yes	18	69.2	23	60.5	41	64.1
No	8	30.8	15	39.5	23	35.9
13. Employment						
Yes	9	33.3	19	50	28	43.1
No	18	66.7	19	50	37	56.9
14. Illness impact on employment***						
Yes	15	60	23	63.9	38	62.3
No	10	40	13	36.1	23	37.7
15. Social/community service utilization						
Yes	19	70.4	26	68.4	45	69.2
No	8	29.6	12	31.6	20	30.8

* 1 missing value
** 2 missing values
*** 4 missing
****Other refers to lesbian/gay, or bisexual

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Table 2: Study Measures for Intervention and Comparison Groups at Baseline

Study Variables	Intervention (N=27*)		Comparison (N=38**)		Significance	
	Mean	SD	Mean	SD	t (df)	*P*
RSES	28.26	6.77	30.45	4.97	-1.504 (63)	.138
MES	74.52	21.48	76.18	20.72	-.315 (63)	.754
MHS	154.78	26.36	154.29	26.49	.073 (63)	.942
SQLS						
Motivation & Energy	37.57	16.82	38.25	15.64	-.169 (63)	.866
Psychosocial	38.83	29.62	36.45	19.85	.363 (63)	.718
Symptoms & Side Effects	19.33	20.40	22.70	18.75	-.688 (63)	.494
GAF	68.88	13.47	70.00	11.82	-.354 (63)	.725
SOFAS	70.27	13.53	70.76	11.99	-.155 (63)	.877

*Of the 27 participants who were recruited for the Intervention Group and who completed the baseline study measures, 5 dropped out, leaving 22 Intervention Group participants.

**Of the 38 participants who were recruited for the Comparison Group and who completed the baseline study measures, 8 dropped out, leaving 30 Comparison Group participants.

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Table 3: Paired-Samples t Tests for Study Measures at Baseline (T1) and Mid-Intervention (T2) for Intervention and Comparison Groups

Group Assignment	T1		T2		Significance	
	Mean	SD	Mean	SD	t (df)	*P*
Intervention Group	N = 20*		N = 20*			
RSES	28.15	7.12	29.30	6.33	-1.878 (19)	.076
MES	75.90	20.84	73.90	20.41	.963 (19)	.348
MHS	154.55	26.38	159.80	25.08	-1.187 (19)	.250
SQLS						
Motivation &Energy	39.29	16.06	34.29	17.28	1.629 (19)	.120
Psychosocial	37.33	27.67	36.17	29.64	.435 (19)	.668
Symptoms & SE[1]	18.28	20.98	19.06	23.56	-.340 (19)	.738
GAF	68.10	12.83	69.95	11.67	-1.065 (19)	.300
SOFAS	69.85	12.06	69.90	13.62	-.038 (19)	.970
Comparison Group	N = 26**		N = 26**			
RSES	30.62	5.31	30.12	5.57	.703 (25)	.488
MES	71.58	17.91	69.69	19.76	.885 (25)	.385
MHS	157.62	27.13	158.35	25.12	-.253 (25)	.803
SQLS						
Motivation &Energy	36.26	12.64	31.57	12.15	1.705 (25)	.101
Psychosocial	35.26	20.80	32.73	18.73	.900 (25)	.377
Symptoms & SE[1]	22.00	18.55	21.38	17.85	.275 (25)	.786
GAF	71.08	11.93	69.72	11.39	.845 (25)	.406
SOFAS	71.27	12.03	69.60	10.98	1.007 (25)	.324

*20 of the 22 Intervention Group participants completed both the T1 & T2 questionnaires (1 participant completed only the T1, T3 & T4 questionnaires; and 1 participant completed only the T1 & T3 questionnaires). Therefore, the above analysis includes only 20 Intervention Group participants.

**26 of the 30 Comparison Group participants completed both the T1 & T2 questionnaires (1 participant completed only the T1, T3 & T4 questionnaires; and 3 participants completed only the T1 & T3 questionnaires). Therefore, the above analysis includes only 26 Comparison Group participants.

[1]SE – Side Effects

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Table 4: Paired-Samples t Tests for Study Measures at Baseline (T1) and Immediate Post-Intervention (T3) for Intervention and Comparison Groups

Group Assignment	T1		T3		Significance	
	Mean	SD	Mean	SD	t (df)	*P*
Intervention Group	N = 17*		N = 17*			
RSES	27.94	7.25	29.76	5.79	-1.923 (16)	.072
MES	77.18	22.74	75.47	22.37	.524 (16)	.607
MHS	156.12	28.84	159.71	26.20	-1.092 (16)	.291
SQLS						
Motivation &Energy	38.45	17.70	31.51	13.20	1.938 (16)	.070
Psychosocial	39.90	31.01	41.08	31.97	-.332 (16)	.744
Symptoms & SE[1]	20.40	21.82	23.16	27.18	-.654 (16)	.523
GAF	68.47	13.60	73.20	14.95	-2.632 (16)	.018
SOFAS	69.88	12.84	73.67	13.02	-2.331 (16)	.033
Comparison Group	N = 23**		N = 23**			
RSES	29.30	4.81	29.09	7.35	.217 (22)	.830
MES	79.83	18.36	78.13	24.34	.461 (22)	.649
MHS	148.96	28.23	147.70	30.98	.436 (22)	.667
SQLS						
Motivation &Energy	41.77	14.74	38.04	15.37	1.482 (22)	.153
Psychosocial	38.12	19.11	35.22	20.27	1.272 (22)	.217
Symptoms & SE[1]	22.15	16.04	19.43	15.25	1.374 (22)	.183
GAF	68.48	12.24	65.61	11.58	1.334 (22)	.196
SOFAS	69.04	12.75	64.61	11.32	2.085 (22)	.049

*17 of the 22 Intervention Group participants completed both the T1 & T3 questionnaires (5 participants completed only the T1 & T2 questionnaires). Therefore, the above analysis includes only 17 Intervention Group participants.

**23 of the 30 Comparison Group participants completed both the T1 & T3 questionnaires (2 participants completed only the T1, T2 & T4 questionnaires; and 5 participants completed only the T1 & T2 questionnaires). Therefore, the above analysis includes only 23 Comparison Group participants.

[1]SE – Side Effect

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Table 5: Paired-Samples t Tests for Study Measures at Immediate Post-Intervention (T3) and 4-Weeks Post-Intervention (T4) for Intervention and Comparison Groups

Group Assignment	T3		T4		Significance	
	Mean	SD	Mean	SD	t (df)	*P*
Intervention Group	N = 15*		N = 15*			
RSES	29.67	6.04	31.00	6.91	-2.092 (14)	.055
MES	77.93	22.19	75.53	21.11	.922 (14)	.372
MHS	158.87	26.95	160.93	24.44	-.552 (14)	.590
SQLS						
Motivation &Energy	31.90	13.46	29.05	16.36	1.023 (14)	.324
Psychosocial	41.78	32.68	36.56	27.64	1.066 (14)	.304
Symptoms & SE[1]	24.58	28.71	20.83	24.20	.662 (14)	.519
GAF	73.28	15.79	73.20	15.83	.057 (14)	.955
SOFAS	73.78	13.91	73.60	14.81	.185 (14)	.856
Comparison Group	N = 18**		N = 18**			
RSES	28.94	8.12	29.06	8.02	-.166 (17)	.870
MES	79.33	26.30	77.28	25.91	.962 (17)	.350
MHS	146.89	33.30	148.72	28.28	-.527 (17)	.605
SQLS						
Motivation &Energy	37.50	16.94	36.71	16.43	.304 (17)	.765
Psychosocial	34.35	22.38	35.74	23.17	-.534 (17)	.601
Symptoms & SE[1]	18.75	15.72	19.79	18.22	-.551 (17)	.589
GAF	64.61	11.87	64.14	11.45	.317 (17)	.755
SOFAS	63.61	11.91	63.44	8.61	.086 (17)	.932

*15 of the 22 Intervention Group participants completed both the T3 & T4 questionnaires (1 participant completed only the T1, T2 & T3 questionnaires; 5 participants completed only the T1 & T2 questionnaires; and 1 participant completed only the T1 & T3 questionnaires). Therefore, the above analysis includes only 15 Intervention Group participants.

**18 of the 30 Comparison Group participants completed both the T3 & T4 questionnaires (2 participants completed only the T1, T2 & T3 questionnaires; 2 participants completed only the T1, T2 & T4 questionnaires; 5 participants completed only the T1 & T2 questionnaires; and 3 participants completed only the T1 & T3 questionnaires). Therefore, the above analysis includes only 18 Comparison Group participants.

[1]SE – Side Effects

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