

Perspective

Service Engagement in First-Episode Psychosis: Current Issues and Future Directions

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Nous célébrons 60 ans

It has been reported that up to 50% of patients receiving mental health services disengage from treatment, with adolescents and young adults being particularly at high risk. Even in the context of specialized services in youth mental health, such as early intervention programs for psychosis, disengagement rates remain high. There is a need for extensive and innovative efforts to address the issue of service disengagement in first-episode psychosis (FEP). A multi-dimensional understanding of the phenomenon of engagement can help to inform the development of strategies to address this important clinical issue. In our paper, we propose a conceptual framework for understanding service engagement, provide an overview of the issues pertaining to service engagement in FEP, and suggest future directions for research and practice.



L'engagement aux services dans le premier épisode de psychose : enjeux actuels et futures orientations

Des rapports indiquent que jusqu'à 50 % des patients qui reçoivent des services de santé mentale se désengagent de leur traitement, et que les adolescents et les jeunes adultes sont particulièrement à risque élevé. Même dans le contexte des services spécialisés en santé mentale des jeunes, comme les programmes d'intervention précoce pour la psychose, les taux de désengagement demeurent élevés. Il faut de vastes initiatives innovatrices pour aborder la question du désengagement des services au premier épisode de psychose (PEP). Une explication multidimensionnelle du phénomène de l'engagement peut contribuer à éclairer l'élaboration de stratégies en vue de résoudre cet enjeu clinique important. Notre article propose un cadre conceptuel pour comprendre l'engagement aux services, offrir un aperçu des questions relatives à l'engagement aux services dans le PEP, et suggérer des orientations futures pour la recherche et la pratique.

Service disengagement is a clinical challenge that continues to afflict the mental health care system. It has been reported that up to 50% of patients receiving mental health services disengage from treatment, contributing to poor outcomes and escalating health care costs.^{1,2} Disengagement rates in mental health services are higher than those associated with other medical services.³ Currently, there are no universally accepted definitions for mental health service disengagement and engagement, although typically they are assessed using proxies, such as attendance, treatment drop out, therapeutic alliance, and treatment adherence.²⁻⁵ However, these proxies constitute a simplistic, obverse approach to understanding a rather complex phenomenon, and do not necessarily provide insight on how to clinically and comprehensively address the challenge of engagement.

It is important to understand engagement as a dynamic phenomenon that changes in relation to stages of treatment and patient needs, and, also, which takes into consideration developmental factors. In our paper, we propose a conceptual framework for understanding engagement, provide an overview of the issues and implications of service disengagement, particularly in young people diagnosed with an FEP, and suggest future directions for research and practice to optimize engagement in FEP.

Understanding Engagement as a Multi-dimensional Construct

A multi-dimensional framework can help to highlight diverse factors that are important for understanding engagement. A nuanced conceptualization could incorporate

several dimensions related to engagement. These include engagement in relation to the continuum of care, for example, patients may minimally engage or not engage at the onset of treatment, after a period of receiving treatment, and (or) during transfer of services; engagement in relation to types of services received, for example, with case management services, medication interventions, or group therapies; pattern of engagement, for example, disengaging from services and then re-engaging with services over a period of time; engagement in relation to duration, in other words, length of time participating in services before beginning to disengage; and patient and family perceptions of engagement. There is some evidence that the risk of disengagement is higher when patients are initiating treatment or transferring to another service.^{5,6} This last dimension highlights the importance of striking a balance between engagement efforts of service providers and perceived need and satisfaction of patients and families. For example, patients may attend appointments and participate in treatment, but may feel disempowered by, or dissatisfied with, the services they receive, which can be a precursor to service disengagement.

Service Disengagement in First-Episode Psychosis

Adolescents and young adults are at high risk for disengaging from mental health services.^{1,2,7} This is of particular concern for young people with psychotic disorders, given that the peak onset for these disorders occurs during adolescence and young adulthood, and given that the outcome trajectories are established relatively early, usually during the first 2 to 5 years from illness onset.⁸ Specialized programs for FEP have placed a specific emphasis on service engagement, with the ultimate goal of achieving symptom remission, relapse prevention, and social recovery.⁹⁻¹⁴ Treatment is delivered by a multidisciplinary team, typically using an intensive case management model, and includes medication (usually second-generation antipsychotics) and psychosocial interventions addressing illness education, lifestyle management, family intervention and support, relapse prevention, and return to school and (or) work.^{9,11-13} Emphasis is placed on interpersonal skills of clinicians in relation to working with young people, providing needs-based treatment in youth-friendly ways,¹¹ and providing care within low-stigma environments, wherein hope and personal potential are given primordial importance.^{9,13}

While the benefits of SEI for FEP, compared with routine care, have been reported in numerous controlled and quasi-experimental studies,¹⁴⁻²³ engagement remains an ongoing issue of concern. A recent systematic review showed that disengagement rates within SEI programs for FEP varied from 20.5% to 40% across studies,⁴ and concluded that

Clinical Implications

- Service engagement is a complex and dynamic phenomenon that changes in relation to stages of treatment, patient needs, and developmental factors.
- Adolescents and young adults, including those receiving specialized services for treatment of FEP, are at high risk for service disengagement.
- There is a need for innovative efforts to address the issue of engagement in youth mental health service delivery. Peer support and new technologies may provide avenues for optimizing service engagement, but require further research on how these approaches can be integrated within models of care.

Limitations

- This discussion is not based on a systematic review of the literature.
- The general paucity of research in the field of service engagement, for example, from the perspectives of young patients, families, and service providers, limits a more detailed and nuanced analysis.

about 30% of people disengage from treatment despite ongoing therapeutic need. The issue of engagement is present across the continuum of care: engaging patients into treatment, sustaining their engagement over time, and maintaining engagement during the transfer from specialized SEI services to routine care.

Factors Influencing Disengagement Among Young People With First-Episode Psychosis

Several factors influencing disengagement have been reported in the FEP literature, including duration of untreated psychosis, symptom severity, insight, diagnoses of nonaffective psychosis, forensic history, substance use, and the presence of family support,^{4,24,25} with the latter 2 identified in a systematic review as being the most robust predictors.⁴ Some of these factors are consistent with those reported in the broader mental health literature on service engagement (for example, forensic history, comorbid substance use, and limited insight).²

Ethnicity, culture, and social deprivation have been given limited attention in relation to service engagement and yet may be of particular significance in many jurisdictions within Canada, given the multi-ethnic and diverse nature of the population in most urban settings. A review by Doyle et al⁴ identified only 2 studies that examined ethnicity^{25,26} with inconsistent findings. However, within the broader mental health literature, ethnic minority background and social deprivation (for example, homelessness) are commonly reported sociodemographic factors associated with service disengagement. Service engagement challenges may also be related to the mental health system, the level of integration between components of the system (primary, compared with specialized, care), patients' willingness to accept treatment, the interpersonal skills of service providers,⁹ and the types of interventions delivered in relation to patients' needs;

Abbreviations

FEP	first-episode psychosis
SEI	specialized early intervention

however, these types of service- and system-related factors have not been given much attention in the FEP literature.

Stakeholder Perspectives on Reasons for Disengagement

While the FEP literature has examined characteristics of patients who disengage from treatment, less research has been focused on the reasons for disengagement² from the perspectives of patients, their families, and service providers. For example, in a systematic review on disengagement in FEP, none of the studies provided information regarding the reasons patients dropped out of treatment.⁴ Within the broader mental health literature, Smith et al²⁷ conducted qualitative interviews with 56 participants diagnosed with schizophrenia, schizoaffective disorder, or bipolar disorder who had disengaged from mental health care, and interviewed their service providers as well. Patients commonly expressed the following reasons for disengagement: services not being relevant for their needs, lack of trust toward service providers, and believing they were not ill. Providers highlighted insight, language and cultural barriers, and stigma as the main reasons. The differences in reasons ascribed by these 2 groups lend support to the importance of examining this issue from different perspectives.

Qualitative investigations with young people diagnosed with FEP illustrate that they have a multi-dimensional perspective of their recovery and well-being that includes illness-related, social, moral, physical, and material or financial dimensions, and that meaningful activity engagement is also core to this process.²⁸⁻³¹ However, service providers may place more emphasis on symptom recovery and illness education, while not being attuned to addressing other aspects, such as social, physical, and meaningful activity engagement.

Measuring Engagement in First-Episode Psychosis

Currently, there are no universally accepted definitions for service engagement and disengagement, although typically they are assessed using proxies, such as attendance, therapeutic alliance, and treatment adherence.^{2,4} Inconsistencies in how these concepts are operationally defined and measured may be one contributing factor explaining the variation of disengagement rates seen across studies in the FEP literature.⁴ A common measure of service engagement used in the FEP literature is the Service Engagement Scale.³² This 14-item scale was developed based on a review of the literature and clinical practice observations and then tested within the context of an FEP population. Service engagement is assessed by measuring provider reports of client availability, collaboration, help seeking, and adherence. However, the extent to which young people with FEP would agree that these domains are salient for their engagement is unclear. This would be an important area to examine through the pursuit of both

qualitative and quantitative investigations; however, to date, very few studies have focused on young people's experiences of early intervention services, even in general terms,³³ let alone the factors considered to be most important for influencing their engagement with services across time.

Future Directions for Research and Practice

As a starting point to developing and implementing strategies to enhance engagement in FEP, future research could focus on understanding the experiences and perspectives of young people, families, and service providers in relation to service engagement. This knowledge can help inform the development of an operational and patient-oriented definition of service engagement that can then be used to guide future studies. Moreover, qualitative attention is warranted on the reasons patients have for engaging and disengaging with services, factors each stakeholder group perceives as salient in relation to enhancing and hindering engagement, and the extent to which perspectives on engagement vary among patients, families, and service providers. Such knowledge can be used to examine the extent to which currently available measures of service engagement are patient- and family-oriented.

The multi-dimensional framework we described above could inform the areas of inquiry for such an investigation, for example, consideration of patient experiences and perspectives of engagement in relation to different phases of illness, treatment, and in relation to different types of services they receive. Future research should also focus on evaluating the effectiveness and cost-effectiveness of strategies for enhancing service engagement. For example, examining whether peer support and leveraging information and communication technologies, that are consistent with the developmental culture of youth growing up in the 21st century, can help to enhance service engagement across the continuum of care for FEP.

Developing and Implementing Strategies to Enhance Engagement in First-Episode Psychosis

Given the complex and dynamic nature of engagement, a multi-dimensional approach to addressing engagement is warranted. Engagement strategies can be targeted to patients, families, service providers, and the system. Among patients and families, engagement strategies can be focused on early assessment of barriers to engagement and enhancing motivation for treatment (for example, perceived need for treatment, confidence in treatment, and perceived ability to participate in treatment). Service providers can be trained on how to assess barriers to engagement with patients and families and how to address these barriers using, for example, brief motivational interviewing techniques.³⁴ Enhancing service providers' capacities in expressing caring, respectful, and nonjudgmental attitudes toward patients is also identified as a strategy in the qualitative literature to increase engagement.²⁷ Services

need to be flexible and clinicians may need to be flexible in how, when, and where services are delivered, and which components of services are delivered over time. Service providers, patients, and families may have different ideas on which issues treatment and services should focus. In this regard, engagement strategies would be to discuss and agree on common goals and present treatment as a step toward achieving patients' defined goals.

At the system level, engagement strategies can target the accessibility of services, for example, in relation to transportation assistance, scheduling flexibility, location, and timing of service delivery.²⁷ Services should be quick and easy to access, as opposed to the complex and traumatic pathways many young patients experience in the process of accessing mental health services, for example, through emergency departments and judicial systems. Leveraging Internet, mobile technologies, and social media may provide an avenue to address service accessibility. However, to date, early intervention services for psychosis have been restricted to models of care that are delivered in person at a clinic or in the community. Given that more than 95% of adolescents and young adults use the Internet, increasingly through mobile devices,³⁵ these technologies offer opportunities to provide services through a nonintensive and arguably a more engaging format that is commensurate to the developmental culture of young people growing up in the 21st century. Preliminary surveys with patients with FEP indicate that they are enthusiastic about using Internet-based interventions as part of the mental health services they receive.³⁶ Research also suggests that people with psychotic disorders are receptive to using technology to connect with service providers as well as their peers.^{36–38} This is further supported by studies showing that patients with FEP commonly identify peer support as a highly valued service.^{31,39,40}

Lindsey et al⁴¹ examined 40 randomized controlled trials for strategies targeting the engagement of families in youth mental health services, which are also pertinent for this discussion. Among 22 strategies, assessing clients' strengths and needs, making services convenient to access, providing education about services, providing meaningful homework tasks, and assessment of treatment barriers showed the most promise in terms of impact, respectively. In a qualitative study,²⁷ patients highlighted that having services that address needs from a holistic and instrumental perspective (for example, help to return to work and school) can be a useful strategy for engagement. Targeting social and vocational outcomes has been proposed as a way to better meet the needs of young people in international youth mental health reform initiatives.⁴² Indeed, it may be important for service providers to recognize and convey to patients and families that treatment is part and parcel of a broader process toward recovery that is ideally shaped and driven by patients' personal and social goals. International reform of youth mental health service initiatives have highlighted other key features to better meet the needs of young people, including youth participation in service

planning, implementation, evaluation, and research. Youth participation can help to inform the design of youth-friendly environments and services, which, in turn, can facilitate engagement.⁴¹

Summary

Service engagement is a critical issue for SEI in psychiatry. The construct of engagement is complex, and we propose that an in-depth, multi-dimensional understanding of engagement be considered. We have highlighted several elements of engagement that can be considered for research and practice. Service-, system-, and cultural-level factors warrant further attention, and future research should also focus on understanding the issue of engagement and disengagement from the perspectives of patients, families, and service providers. Developing knowledge on the issue of engagement from the perspectives of key stakeholder groups can then help to assess the extent to which current practices and measures of service engagement are consistent with stakeholder perspectives. Future research could also focus on whether peer support and leveraging technology consistent with youth developmental culture in the 21st century can help to enhance service engagement across the continuum of care for FEP, and how these approaches can be integrated within new models of care.

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