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Structural Disadvantage and Culture, Race, and Ethnicity in Early Psychosis Services: International Provider Survey

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Abstract

Objective: Little is known about provider perspectives on programmatic responses to structural disadvantage and cultural differences within early intervention in psychosis (EIP) services, programs, and models. The primary objective of this study was to investigate providers' perspectives on the impacts of disadvantage and minority race, ethnicity, and culture and to describe current practices and perceived gaps and concerns.

Methods: An online survey of specialized EIP providers was disseminated in the United Kingdom, United States, Canada, Australia, and Chile. A total of 164 providers, representing 110 unique sites, completed the survey. Closed-ended questions gathered demographic and program data, including information on formal assessment of trauma or adversity, integration of trauma-informed care, integration of formal cultural assessment tools, training focused on culture, programmatic changes to address culture-related issues, and consultation with cultural insiders. Open-ended questions addressed the demographic mix of the program's client population; the perceived role and influence of trauma, structural disadvantage, and cultural differences; and concerns and needs related to these topics. Frequencies were examined for closed-ended items; open-ended responses were systematically coded.

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Results: Overall, survey findings suggested low levels of implementation of a variety of assessment and support practices related to cultural diversity in EIP programs. Coding of openended responses revealed numerous concerns regarding the impacts of disadvantage and cultural difference on clients and perceived gaps in policy and implementation.

Conclusions: An expansion of research and service development aimed at better meeting the disadvantage- and culture-related needs of young people with early psychosis and their families should be a priority for the field.

Over the past decade, specialized early intervention in psychosis (EIP) services have expanded substantially, supported by national initiatives in a growing number of countries (1). Research studies have consistently found positive impacts of EIP on multiple domains, including significant improvements in clinical and functional recovery at the time of discharge (2). Neither positive outcomes nor sustained engagement is universal, however, and a growing body of work has found that adversity, structural disadvantage, and racial-ethnic discrimination predict poorer outcomes and service disengagement (3–6).

A substantial body of research suggests that structural disadvantages (e.g., poverty and residential segregation) and culture-related adversities (e.g., migration, asylum, and racial profiling) heighten the risk for developing psychotic symptoms (7–13). Independently of psychosis, these adverse experiences are widely considered to be risk factors for educational underattainment, unemployment, poor general medical health, and incarceration (14–17). Furthermore, within the broader psychosis literature, poverty and minority race-ethnicity have been found to be associated with disparities in access to and quality of care (18, 19), including higher rates of involuntary hospitalization (20, 21) and disability (22, 23). Recent studies also suggest that both the form and the content of psychotic symptoms, including auditory hallucinations, can be shaped by adverse experiences as well as by culture and race-ethnicity, sometimes in ways that render these experiences more distressing (24–27).

Although contemporary epidemiology has helped dispel myths about schizophrenia as an "equal opportunity" disorder that equally affects young people of all classes (28), schizophrenia does emerge across socioeconomic lines, albeit not at equal rates. EIP programs, particularly programs with no income-based eligibility restrictions, therefore serve a heterogeneous mix of clients, all with early psychosis but some with multiple additional cultural, socioeconomic, and structural challenges.

In recent years, the EIP research community has begun to innovate and expand its research base in the areas of trauma-related services (29–32), cultural assessment and adaptation (33, 34), and intervention focused on poverty and un-employment (9, 35, 36). Specific examples include therapies tailored to treat trauma in early psychosis (29, 30), cultural adaptation of therapies for psychosis (33), and development of an EIP service explicitly focused on unstably housed youths (36). Compared with many other areas of EIP treatment, however, interventions in these areas remain underdeveloped. In addition, little is known about the international landscape of EIP implementation in these practice areas, particularly in community-based clinics, and about the concerns of frontline clinicians, in particular those operating outside academic research settings.

To better understand the gaps in the literature described above, we developed a mixedmethods project to explore the current international implementation landscape of EIP policies and practices relevant to disadvantage and cultural competency. We also sought to elucidate providers' views on the role and impact of disadvantage and culture, promising or innovative practices and strategies, and challenges, concerns, and unmet needs in program engagement and service- related outcomes.

METHODS

Study Design

Our mixed-methods design was conducted in three phases. First, we conducted informal EIP provider interviews to develop an initial provider survey and accompanying qualitative interview protocol. The survey was then vetted and finalized by an independent group of EIP providers. The survey was disseminated online and was active between September 2017 and January 2019. We also conducted in-depth follow-up interviews to deepen our understanding of survey findings (interviews will be reported on in a separate study). Recruitment methods included e-mails sent to all program directors publicly listed in national and international directories and flyers disseminated via national and regional early psychosis Listservs.

Participants

The survey targeted providers working in specialized EIP services; 164 participants completed the survey and were included in the analyses. Participants represented programs in 110 unique cities or catchment areas (e.g., National Health Services Trusts) in the United States, United Kingdom, Canada, Australia, and Chile.

Survey Items and Measures

The survey gathered demographic data of participants, including age, race-ethnicity, gender, highest degree completed, and program role. Program variables reported by participants were program location, model followed, and inclusion of peer workers, vocational specialists, and family peers or partners. To assess disadvantage-related policies and practices, the survey included yes-or-no questions regarding integration of formal assessment of trauma or adversity and about integration of policies focused on trauma-informed care. To assess culture-related policies and practices, the survey included yes-or-no questions about integration of formal cultural assessment tools, training focused on culture and early psychosis, programmatic changes made in response to culture-related issues, and consultation with cultural insiders with respect to both individual clients and the program more broadly. Six open-ended questions were included regarding the demographic mix of the program's client population, the role and influence of trauma, structural disadvantage, and cultural differences, and concerns and needs related to these topics. (The exact text of all survey items discussed here is available in an online supplement to this article.)

Analysis

Closed-ended questions.—Quantitative variables were exported from Qualtrics into Stata, version 15. A minimum "unique location count" of programs was generated on the basis of self-reported program name, city, state, province, or region. Frequencies were

computed for roles and key program policy and practice variables, and distributions were examined by country.

Open-ended questions.—Open-ended responses were imported into Atlas.ti qualitative software for analysis. We adopted a systematic content analysis approach with the goal of comprehensively coding all open-ended responses (37). Both a priori and emergent codes were used; examples of a priori codes included codes directly tied to survey questions (e.g., "higher disengagement attributed to low socioeconomic status" and "higher disengagement attributed to low socioeconomic status" and "higher disengagement attributed to minority race-ethnicity"). Emergent codes reflected areas and topics identified through open coding—for example, "ethnocentric bias in underlying EIP frameworks." The codebook was developed through an initial open-coding round with a subset of the data, refined and tested in a new sample, and finalized. After formal reliability checks were conducted (κ =0.85), remaining survey responses were coded. As an additional safeguard that ensured that no relevant codes were missed, systematic keyword searches were conducted. This process yielded only a very small number of additions or corrections.

RESULTS

Sample

Participant program affiliations, roles, and demographic characteristics are listed in Table 1. Overall, the 164 participants represented 110 unique EIP locations (i.e., cities, towns, or health service regions), including one site in Chile, 18 in the United Kingdom (including England, Scotland, and Northern Ireland), 10 in Canada (primarily in Ontario and Quebec), four in Australia, and 77 in the United States. To put these numbers in context, at the time the survey was completed, an estimated 254 programs existed in the United States, six in Australia, 60 trusts or boards with EIP services in the United Kingdom, 80 sites in Canada, and one site in Chile (38–44). Penetration by country thus ranged from 100% in Chile and 60% in Australia, to 30% in the United States, 30% in the United Kingdom, and 13% in Canada.

Closed-Ended Responses

Frequencies and percentages for role and policy and practice variables are reported for unique program locations by country in Table 2, along with omnibus (i.e., Fisher's exact test) significance analyses. Overall, policies and practices related to adversity and cultural diversity were present in only a minority of programs, with significant variation in overall rates by country.

Open-Ended Responses

Qualitative findings were organized into four sections: program populations, role and impact of disadvantage and cultural difference, emergent strategies and promising practices, and perceived challenges, concerns, and unmet needs. Denominators reflected the number of respondents to the applicable open-ended question, which ranged from 88 to 132. Where denominators would not make sense (as in themes derived from multiple questions with varying response rates), we provide a straight frequency count. Note that because these were open-ended responses, our analysis could include only the textual responses provided by

Program populations.—In total, 99 of 132 (75%) of respondents described their programs as serving significant numbers of clients from ethnic-racial minority communities or structurally and economically disadvantaged communities. Many respondents emphasized that disadvantage and culture intersect, particularly in the context of refugees, asylum seekers, and historically marginalized indigenous populations. As might be expected, the demographic factors of minority populations varied enormously by site and region, with "Travelers" (i.e., itinerant groups, such as Irish Travelers or Romany gypsies) referenced only in the United Kingdom and indigenous-aboriginal clients referenced primarily in Canada and Australia. In the United States, large African American or Latinx populations were the most common minority constituencies.

Role and impact of disadvantage and cultural difference.—The overwhelming majority of respondents described impacts of disadvantage and cultural difference on program engagement and service-related outcomes. Example quotations for each major area are provided in Table 3.

Overarching Impacts on Program Benefits and Engagement

With respect to program disengagement, 65% (82 of 126) of respondents (83% of those in programs with substantial minority or disadvantaged populations) reported higher rates of treatment disengagement tied to race, ethnicity, culture, or disadvantage. Specific populations mentioned varied by participant and included clients from aboriginal or indigenous communities, Blacks of African origin, Latino and Latina groups in the United States, Travelers in the United Kingdom, refugees and asylum seekers, and those experiencing socioeconomic hardship. Twenty-seven participants specifically described higher rates of family disengagement, particularly among recent immigrants and specific cultural minority communities subject to a history of marginalization or exclusion within the region in question.

Moreover, 59% (78 of 132) of participants described poverty or socioeconomic disadvantage as factors that made it significantly more difficult, even for clients and families who remained with the program, to fully benefit from interventions; 77% (96 of 124) said the same of particular racial-ethnic or cultural minority groups, with many underscoring the intersectionality of culture and disadvantage. With respect to poverty, participants cited the need to prioritize basic needs over participation in more psychological interventions, as well as spillover stressors of living in neighborhoods with high rates of poverty, drug trafficking, and violence and having heightened risks of direct criminal justice system involvement. In the area of culture, 36% (45 of 124) specifically mentioned that clients' and families' alternative cultural explanatory frameworks or distrust of conventional mental health services or interventions were major barriers. In addition, many participants noted the adverse impact of fears related to deportation for those not yet permanently settled and lack of full access to either health care or social welfare benefits. Overall, 19% (24 of 124) specifically mentioned community cultural stigma (toward psychosis or mental health

treatment participation), with some participants noting that some clients or families who were from very small cultural minority groups were so apprehensive about community attitudes that they were afraid even to use interpreters in psychiatric care, citing concerns about the rumors that would spread.

Emerging Strategies and Promising Practices

Across the board, virtually all participants who described concrete strategies or practices related to structural disadvantages mentioned standard case management practices including assistance with welfare applications and linkage to subsidized housing and social welfare supports. At least 10 participants, however, explicitly mentioned that linkage to such programs was often inadequate to meet clients' actual needs—for example, because of local housing shortages, lengthy waitlists, or high legal barriers.

At least some participants nevertheless described strategies and practice principles that appeared to go well beyond conventional individual case management or cultural competency trainings; a list of these strategies and textual examples are provided in Table 4. Strategies noted ranged from implementation of culturally adapted trauma interventions to intentional program placement and colocation and direct involvement with minority communities. Many respondents also emphasized the importance of culturally diverse teams and teams that include peer and family providers.

Perceived Challenges, Concerns, and Unmet Needs

Overall, participants called attention to a wide range of concerns related to social and structural disadvantages and cultural differences within their programs and the field more broadly. Responses ranged from brief acknowledgments of gaps in available interventions, trainings, and re- sources to detailed critiques. Thematic areas of concern or unmet need (beyond brief acknowledgment of a general lack of availability of resources or trainings) and textual examples are provided in Table 5.

Coding across open-ended questions indicated that 99 (60%) of the respondents identified at least one area of concern or unmet need related to addressing disadvantages and cultural differences and their intersections within early intervention services. Overall, many participants, including those working on programs with at least some form of structured culture training and policy, explicitly noted the challenges of actually enacting or operationalizing even those principles that are, in theory, widely accepted (such as the general goal of "cultural competency"). Such comments were especially common in discussions of model or team navigation of alternative explanatory frameworks or the personal and cultural meanings that might be ascribed to experiences of psychosis.

For example, one participant described a client whose belief in reincarnation was interpreted as a symptom of psychosis:

A client of ours is of Pacific Island descent. The client believes in reincarnation. Her narrative involves a story of conflict with Japanese ancestors. The therapist insists on calling this the client's "delusion." My concern is that this young woman's experience has been dismissed by the therapist. Were the therapist to

[actually] approach this young woman's experience with cultural humility and openness, together they might create more respect and healing within the possible context of the client's belief system.

Finally, it is worth noting that many participants felt that it was not just lack of engagement with specific cultural communities that was a problem but a broader lack of engagement with experientially grounded roles and perspectives. For example, many participants recommended more universal inclusion of peer and family-peer roles, as well as involvement of service users, families, and communities in service planning and design.

DISCUSSION

In this article, we present what is, to the best of our knowledge, the only international study of program policies and practices, examining providers' views regarding the impact of structural disadvantage and cultural difference in EIP services on program engagement and service-related outcomes and providers' concerns about unmet needs. Quantitatively, we found that key program-level practices investigated in these domains, including assessment of childhood adversity and cultural formulation, were present in only a minority of programs. Most participants described substantive impacts of disadvantage and cultural difference on patients' program engagement and ability to benefit from EIP services. Participants delineated both promising practices and a range of concerns regarding the underdevelopment of training, policy, and interventions related to these topics in EIP practice. On a hopeful note, a small subset of participants also described potentially powerful ways of engaging diverse communities and addressing structural disconnects.

As noted in the introduction, a substantial literature exists on the epidemiological role of disadvantage, migration, and culture (7-13). In comparison, far fewer studies are available regarding the development of practice components designed to address clinical and programmatic challenges related to these issues. Findings reported here indicate a need for greater attention to these topics, including training and intervention development, consultation with relevant community and service user stakeholders, greater diversity of EIP team members, and development of strategies to increase the engagement of members of marginalized cultural and linguistic minority groups. As suggested by participants' comments regarding existing training models and manuals, in some cases a reevaluation of the extent to which these materials support deeper cultural and structural competencies (45, 46) seems in order. Ideally, all such efforts to reevaluate and, where necessary, develop new interventions or resources would be developed hand in hand with key community stakeholders, including service users and their family members. With respect to cultural difference, challenges tied to the navigation of alternative cultural frameworks suggest the potentially widespread value of additional development work in this area-work that, again, would strongly benefit from collaborative approaches or coproduction.

Most participants described disadvantages, cultural differences, and their intersections as major drivers of disengagement and disparities in young people's ability to equally benefit from EIP services. Although some recent studies, as noted in the introduction, have identified these variables as key predictors of engagement and functional outcomes (24–

27), other studies and reviews have not or have not included variables directly relevant to these topics in primary data collection (47–56). A 2012 systematic review of studies investigating predictors of relapse in first-episode psychosis, for example, identified only a small number of variables relevant to trauma, structural disadvantages, and cultural differences included in the extant research, and even these were present in only a few studies (57). A systematic review of service user priorities for measurement identified no such studies (58). We were likewise unable to identify any existing studies regarding the EIP-related measurement priorities of socioeconomically disadvantaged or racial-ethnic minority communities. These discrepancies between participants' testaments to the influence of adversity and cultural difference—which were at times emphatic—and the constructs tapped in standard measurement batteries suggest a potential need to reevaluate core measurements. In addition, more extensive and diversified qualitative work (in research contexts) and consultation (in quality improvement efforts) aimed at achieving a deeper understanding of why certain groups of service users and families opt to disengage from EIP services seems warranted.

Finally, participants' emphasis on the nuanced challenges of "actualization" or implementation underscores the need for thoughtful strategies that go well beyond "one touch" training or technical assistance. Here, the innovative and emerging practices described by a select subset of participants help illuminate more substantive ways forward, including structural solutions, such as physically locating programs in neighborhoods with the highest need, high rates of poverty, or the greatest racial-ethnic diversity; developing or integrating meaningful culturally adapted or culturally targeted interventions or practices; and deeply engaging with diverse communities and community stakeholders, including both consultation and team member involvement in relevant local communities.

Although the term "structural competency" appeared only once in participant responses, the many comments regarding intersections of race-ethnicity, class, and historical exclusion and the ways in which these intersections shape both trajectories of individual service users and service organization also point to the potential value of integrating pedagogical and intervention strategies developed within the structural competency movement (59). Like the promising practices identified by our participants, many structural competency implementations have focused on getting providers out into affected communities and directly engaged with key communities (60) and in other cases have adopted a version of the "flipped classroom" that places community members and diverse service users in a primary educator role (61).

This study had some limitations. A primary limitation was reliance on a convenience sample of EIP programs and providers. Response rates relative to estimated program numbers ranged from 12.5% to 100% across various countries, with 30% of U.S. sites (as of 2018) participating. Within the sample, representation was also uneven across demographic groups —for example, three-quarters of participants were White, and 81% had a master's degree or higher. These potential threats to external validity must nevertheless be counterbalanced by the absence of any other extant data, including a similarly large international sample, and by the insights into perspective afforded by open-ended responses, the purpose of which is

not generalizability but rather a deeper understanding of social and, in this case, clinical and organizational phenomena.

CONCLUSIONS

Findings suggest significant gaps and challenges related to equitably engaging and meeting the needs of clients and families from racial-ethnic and cultural minority groups and those experiencing poverty or other structural disadvantages. Research on the client and family experience of EIP services, how such programs intersect with these topics, how they affect engagement, and potential strategies and innovative practices should be prioritized, along with more widespread assessments of acculturation, previous adversity, and socioeconomic and structural disadvantages.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

REFERENCES

- 1. Csillag C, Nordentoft M, Mizuno M, et al. : Early intervention services in psychosis: from evidence to wide implementation. Early Interv Psychiatry 2016; 10:540–546 [PubMed: 26362703]
- Correll CU, Galling B, Pawar A, et al. : Comparison of early intervention services vs treatment as usual for early-phase psychosis: a systematic review, meta-analysis, and meta-regression. JAMA Psychiatry 2018; 75:555–565 [PubMed: 29800949]
- Conus P, Cotton S, Schimmelmann BG, et al. : Pretreatment and outcome correlates of sexual and physical trauma in an epidemiological cohort of first-episode psychosis patients. Schizophr Bull 2010; 36:1105–1114 [PubMed: 19386579]
- Jones N, Godzikovskaya J, Zhao Z, et al. : Intersecting disadvantage: unpacking poor outcomes within early intervention in psychosis services. Early Interv Psychiatry 2019; 13:488–494 [PubMed: 29076244]
- 5. Maraj A, Veru F, Morrison L, et al. : Disengagement in immigrant groups receiving services for a first episode of psychosis. Schizophr Res 2018; 193:399–405 [PubMed: 28803848]
- Reynolds S, Brown E, Kim DJ, et al. : The association between community and service level factors and rates of disengagement in individuals with first episode psychosis. Schizophr Res 2019; 210: 122–127 [PubMed: 31176534]
- Fisher HL, Jones PB, Fearon P, et al. : The varying impact of type, timing and frequency of exposure to childhood adversity on its association with adult psychotic disorder. Psychol Med 2010; 40: 1967–1978 [PubMed: 20178679]
- Heinz A, Deserno L, Reininghaus U: Urbanicity, social adversity and psychosis. World Psychiatry 2013; 12:187–197 [PubMed: 24096775]
- 9. Morgan C, Hutchinson G: The social determinants of psychosis in migrant and ethnic minority populations: a public health tragedy. Psychol Med 2009; 40:1–5
- O'Donoghue B, Roche E, Lane A: Neighbourhood level social deprivation and the risk of psychotic disorders: a systematic review. Soc Psychiatry Psychiatr Epidemiol 2016; 51:941–950 [PubMed: 27178430]
- Oh H, Cogburn CD, Anglin D, et al. : Major discriminatory events and risk for psychotic experiences among Black Americans. Am J Orthopsychiatry 2016; 86:277–285 [PubMed: 26963179]
- 12. Selten JP, van der Ven E, Termorshuizen F: Migration and psychosis: a meta-analysis of incidence studies. Psychol Med 2020; 50: 303–313 [PubMed: 30722795]

- Varese F, Smeets F, Drukker M, et al. : Childhood adversities increase the risk of psychosis: a meta-analysis of patient-control, prospective- and cross-sectional cohort studies. Schizophr Bull 2012; 38:661–671 [PubMed: 22461484]
- 14. Bunting L, Davidson G, McCartan C, et al. : The association between child maltreatment and adult poverty: a systematic review of longitudinal research. Child Abuse Negl 2018; 77:121–133 [PubMed: 29346067]
- Fahy AE, Stansfeld SA, Smuk M, et al. : Longitudinal associations of experiences of adversity and socioeconomic disadvantage during childhood with labour force participation and exit in later adult- hood. Soc Sci Med 2017; 183:80–87 [PubMed: 28475902]
- Lanari D, Bussini O: International migration and health inequalities in later life. Ageing Soc 2012; 32:935–962
- 17. McCrory C, Dooley C, Layte R, et al. : The lasting legacy of childhood adversity for disease risk in later life. Health Psychol 2015; 34:687–696 [PubMed: 25150540]
- Horvitz-Lennon M, Volya R, Garfield R, et al. : Where you live matters: quality and racial/ethnic disparities in schizophrenia care in four state Medicaid programs. Health Serv Res 2015; 50: 1710–1729 [PubMed: 25759240]
- Phillips KL, Copeland LA, Zeber JE, et al. : Racial/ethnic disparities in monitoring metabolic parameters for patients with schizophrenia receiving antipsychotic medications. Am J Geriatr Psychiatry 2015; 23:596–606 [PubMed: 25154537]
- Mann F, Fisher HL, Major B, et al. : Ethnic variations in compulsory detention and hospital admission for psychosis across four UK Early Intervention Services. BMC Psychiatry 2014; 14:256–259 [PubMed: 25214411]
- Mann F, Fisher HL, Johnson S: A systematic review of ethnic variations in hospital admission and compulsory detention in first-episode psychosis. J Ment Health 2014; 23:205–211 [PubMed: 25054369]
- Harvey PD, Heaton RK, Carpenter WT Jr, et al. : Functional impairment in people with schizophrenia: focus on employability and eligibility for disability compensation. Schizophr Res 2012; 140:1–8 [PubMed: 22503642]
- Strassnig M, Kotov R, Fochtmann L, et al. : Associations of independent living and labor force participation with impairment indicators in schizophrenia and bipolar disorder at 20-year followup. Schizophr Res 2018; 197:150–155 [PubMed: 29472164]
- 24. Corstens D, Longden E: The origins of voices: links between life history and voice hearing in a survey of 100 cases. Psychosis 2013; 5:270–285
- Luhrmann TM, Padmavati R, Tharoor H, et al. : Differences in voice-hearing experiences of people with psychosis in the USA, India and Ghana: interview-based study. Br J Psychiatry 2015; 206: 41–44 [PubMed: 24970772]
- Peach N, Alvarez-Jimenez M, Cropper SJ, et al. : Trauma and the content of hallucinations and post-traumatic intrusions in first-episode psychosis. Psychol Psychother (Epub ahead of print, March 10, 2020)
- 27. Rosen C, Jones N, Longden E, et al. : Exploring the intersections of trauma, structural adversity, and psychosis among a primarily African-American sample: a mixed-methods analysis. Front Psychiatry 2017; 8:57 [PubMed: 28469582]
- McGrath JJ: Variations in the incidence of schizophrenia: data versus dogma. Schizophr Bull 2006; 32:195–197 [PubMed: 16135560]
- 29. Bendall S, Jackson HJ, Hulbert CA: Childhood trauma and psychosis: review of the evidence and directions for psychological interventions. Aust Psychol 2010; 45:299–306
- 30. Collinetti S, Bendall S, Barclay N, et al. : Clinical outcomes com- paring the Early Psychosis Prevention and Intervention Centre (EPPIC) treatment as usual (TAU) verses Trauma-Informed Psychotherapy for Psychosis (TRIPP) with Melanie: a 3-year longitudinal approach. Early Interv Psychiatry 2016; 10(suppl 1):84
- Hardy A, Swan S, Bradley J, et al. : The "Talking Trauma" Project: implementation of traumainformed care in early intervention in psychosis services. Early Interv Psychiatry 2018; 12(suppl 1):21

- 32. Tong J, Simpson K, Alvarez-Jimenez M, et al. : Distress, psychotic symptom exacerbation, and relief in reaction to talking about trauma in the context of beneficial trauma therapy: perspectives from young people with post-traumatic stress disorder and first episode psychosis. Behav Cogn Psychother 2017; 45:561–576 [PubMed: 28436349]
- Habib N, Dawood S, Kingdon D, et al. : Preliminary evaluation of culturally adapted CBT for psychosis (CA-CBTp): findings from developing culturally-sensitive CBT project (DCCP). Behav Cogn Psychother 2015; 43:200–208 [PubMed: 24382109]
- 34. Jarvis GE, Iyer SN, Andermann L, et al.: Culture and psychosis in clinical practice; in A Clinical Introduction to Psychosis. Edited by Badcock JC, Paulik G. London, Academic Press, 2020
- Bond GR, Drake RE, Luciano A: Employment and educational outcomes in early intervention programmes for early psychosis: a systematic review. Epidemiol Psychiatr Sci 2015; 24:446–457 [PubMed: 25016950]
- 36. Doré-Gauthier V, Côté H, Jutras-Aswad D, et al. : How to help homeless youth suffering from first episode psychosis and substance use disorders? The creation of a new intensive outreach intervention team. Psychiatry Res 2019; 273:603–612 [PubMed: 30731429]
- Hansen H, Braslow J, Rohrbaugh RM: From cultural to structural competency—training psychiatry residents to act on social determinants of health and institutional racism. JAMA Psychiatry 2018; 75:117–118 [PubMed: 29261827]
- 38. Mayring P: Qualitative Content Analysis. Berlin, Freie Universität Berlin, 2004
- 39. Snapshot of State Plans for Using the Community Mental Health Block Grant 10% Set-Aside to Address First Episode Psychosis. Falls Church, VA, National Association of State Mental Health Program Directors, NRI, Inc, 2018
- 40. EPI in British Columbia. Victoria, British Columbia, BC Early Psychosis Intervention Program, 2020. https://www.earlypsychosis.ca/epi-in-british-columbia
- 41. About Us. Toronto, Early Psychosis Intervention Ontario Network, 2020. https://help4psychosis.ca
- 42. Nolin M, Malla A, Tibbo P, et al. : Early intervention for psychosis in Canada: what is the state of affairs? Can J Psychiatry 2016; 61:186–194 [PubMed: 27254094]
- National Clinical Audit of Psychosis. London, Royal College of Psychiatrists, 2020. https://www.rcpsych.ac.uk/improving-care/ccqi/national-clinical-audits/national-clinicalaudit-of-psychosis
- 44. Paz Castaneda C, Mena C, Gonzalez A, et al. : The implementation of psychological interventions in first episode of psychosis services in Chile. Early Interv Psychiatry 2018; 12(suppl 1):224
- 45. Kirmayer LJ, Kronick R, Rousseau C: Advocacy as key to structural competency in psychiatry. JAMA Psychiatry 2018; 75:119–120 [PubMed: 29261839]
- Metzl JM, Hansen H: Structural competency and psychiatry. JAMA Psychiatry 2018; 75:115–116 [PubMed: 29261822]
- 47. Metzl JM, Hansen H: Structural competency: theorizing a new medical engagement with stigma and inequality. Soc Sci Med 2014; 103:126–133 [PubMed: 24507917]
- Albert N, Bertelsen M, Thorup A, et al. : Predictors of recovery from psychosis: analyses of clinical and social factors associated with recovery among patients with first-episode psychosis after 5 years. Schizophr Res 2011; 125:257–266 [PubMed: 21056926]
- 49. Austin SF, Mors O, Secher RG, et al. : Predictors of recovery in first episode psychosis: the OPUS cohort at 10 year follow-up. Schizophr Res 2013; 150:163–168 [PubMed: 23932664]
- Demjaha A, Lappin JM, Stahl D, et al. : Antipsychotic treatment resistance in first-episode psychosis: prevalence, subtypes and predictors. Psychol Med 2017; 47:1981–1989 [PubMed: 28395674]
- Lambert M, Conus P, Cotton S, et al. : Prevalence, predictors, and consequences of long-term refusal of antipsychotic treatment in first-episode psychosis. J Clin Psychopharmacol 2010; 30:565–572 [PubMed: 20814327]
- 52. Lasalvia A, Bonetto C, Lenzi J, et al. : Predictors and moderators of treatment outcome in patients receiving multi-element psychosocial intervention for early psychosis: results from the GET UP pragmatic cluster randomised controlled trial. Br J Psychiatry 2017; 210:342–349 [PubMed: 28302703]

- 53. Leclerc E, Noto C, Bressan RA, et al. : Determinants of adherence to treatment in first-episode psychosis: a comprehensive review. Br J Psychiatry 2015; 37:168–176
- 54. Solmi F, Mohammadi A, Perez JA, et al. : Predictors of disengagement from Early Intervention in Psychosis services. Br J Psychiatry 2018; 213:477–483 [PubMed: 30027874]
- 55. Stowkowy J, Addington D, Liu L, et al. : Predictors of disengagement from treatment in an early psychosis program. Schizophr Res 2012; 136:7–12 [PubMed: 22336955]
- 56. Verma S, Subramaniam M, Abdin E, et al. : Symptomatic and functional remission in patients with first-episode psychosis. Acta Psychiatr Scand 2012; 126:282–289 [PubMed: 22616617]
- Alvarez-Jimenez M, Priede A, Hetrick SE, et al. : Risk factors for relapse following treatment for first episode psychosis: a systematic review and meta-analysis of longitudinal studies. Schizophr Res 2012; 139:116–128 [PubMed: 22658527]
- Byrne R, Davies L, Morrison AP: Priorities and preferences for the outcomes of treatment of psychosis: a service user perspective. Psychosis 2010; 2:210–217
- 59. Hansen H, Metzl JM (eds): Structural Competency in Mental Health and Medicine: A Case-Based Approach to Treating the Social Determinants of Health. New York, Springer, 2019
- 60. Greene JA, Mooney G, Sufrin C: The walking classroom and the community clinic: teaching social medicine beyond the medical school; in Structural Competency in Mental Health and Medicine: A Case-Based Approach to Treating the Social Determinants of Health. Edited by Hansen H, Metzl JM. New York, Springer, 2019
- 61. Suhail-Sindhu S, Patel P, Sugarman J, et al.: Program for Residency Education, Community Engagement, and Peer Support Training (PRECEPT): connecting psychiatrists to community resources in Harlem, NYC; in Structural Competency in Mental Health and Medicine: A Case-Based Approach to Treating the Social Determinants of Health. Edited by Hansen H, Metzl JM. New York, Springer, 2019

HIGHLIGHTS

- Intervention components targeting disadvantage along with cultural and racial-ethnic differences remain underdeveloped within specialized early psychosis services.
- Providers described numerous ways in which trauma, disadvantage, and culture affect client and family engagement and outcomes.
- Survey responses highlight deeper challenges and complexities associated with providing patient- and family-centered care, particularly among groups with non-Western explanatory frameworks.

TABLE 1.

Characteristics of participants (N=164) in a survey of providers of early intervention in psychosis services

Variable	Ν	%
Service model		
OnTrackNY/USA	44	27
NAVIGATE	18	11
EPPIC (Early Psychosis Prevention and Intervention Centre)	21	13
EASA (Early Assessment and Support Alliance)	8	5
Ohio BeST (Best Practices in Schizophrenia Treatment) model	8	5
Open Dialogue	4	2
U.K. National Health Service model	31	19
Montreal EPI (Early Psychosis Intervention)	3	2
Ontario EPI	8	4
Yale STEP (Specialized	2	1
Treatment in Early Psychosis)		
Mass PREP (Prevention and Recovery in Early Psychosis)	3	2
California Felton	3	2
Blended/hybrid model	11	7
Role		
Therapist, psychologist	43	26
Psychiatrist or nurse practitioner (prescriber)	24	25
Case manager (including nurse case manager and vocational support staff)	29	18
Director and team supervisor	54	33
Peer worker	8	4
Research or evaluation staff	7	4
Race-ethnicity		
Hispanic or Latinx	20	12
East Asian origin	3	2
South Asian origin	3	2
Southeast Asian origin	2	1
African or Black	7	4
Caucasian or White	122	74
Middle East origin	1	1
Multiracial	6	4
Female	107	66
Highest level of education		
Secondary school	1	1
Some college	3	2
Bachelor's degree	27	17
Master's degree	85	52
Doctorate (Ph.D., M.D., Psy.D.)	48	29
Age (M±SD)	41.7±10.2	

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	United Sta	United States (N=77)	United Kin	United Kingdom (N=18)	Austral	<u>Australia (N=4)</u>	Chile (N=1)		Canada (N=10)	(N=10)	Total (N=110)	<u>N=110)</u>	
Variable	Z	%	Z	%	Z	%	Z	%	Z	%	Z	%	^a d
Role													
Peer specialist	36	47	7	39	4	100	-	100	5	50	53	48	.005
Vocational specialist	72	94	13	72	4	100	1	100	7	70	78	71	.001
Family peer or family partner	22	29	3	17	3	75	0	,	3	30	31	28	.007
Policies and practices													
Formal trauma and adversity assessment	31	40	10	56	2	50	0	ī	1	10	44	40	.126
Trauma-informed care policies in place	32	42	6	50	3	75	0	ı	3	30	46	42	.034
Formal cultural assessment	16	21	1	9	3	75	0	ı	-	10	21	19	.006
Targeted training on psychosis and culture	25	33	9	33	2	50	1	100	0	,	34	31	.016
Formal cultural competency policy	24	31	9	33	3	75	0	,	0		33	30	<.001
Changes made to culture-related policy in response to emergent challenges	19	25	S	28	3	75	0		б	30	30	27	.183
Consultation with cultural insiders with respect to individual clients or cases	39	51	12	67	4	100	-	100	٢	70	63	57	.110
Consultation with cultural insiders with respect to policy and practice more broadly	24	31	10	56	б	75	0		ю	30	40	36	.003

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Providers' perceptions of impacts of disadvantage and cultural difference on client outcomes

Category	Quotation
Impact of structural and socioeconomic disadvantage	Example 1: "[Poverty] impacts clients and families dramatically. The clients who do not have to worry about anything related to finances at all solely have the ability to focus on their recovery without having to make decisions about prioritizing time to do one thing over another." Example 2: "Socioeconomic disadvantage impacts the people in our programs as it creates a constant state of instability When one's focus is on securing the basic things they need to live, they are not able to focus on other things that are important along the recovery journey. It also refocuses the goals that arise during meetings with professionals from counseling to process or work through their experience, to more case management to address tangible or pressing matters."
Impact of cultural, racial, and ethnic differences	Example 1: "Some individuals of various religious beliefs do not align with the medical model of treatment and are at times resistant to interventions." Example 2: "I have witnessed that my clients of Asian descent do not generally have families that agree with their taking medication for psychosis or accept the diagnosis of schizophrenia spectrum disorders, nor do they tend to participate in the clients' treatment."
Influence of structural and socioeconomic disadvantages on disengagement	Example 1: "It seemed to me that the people who were most likely to disengage from the program were those facing serious, immediate risk related to socioeconomic factors (i.e., housing, poverty). I believe this was related to the fact that they saw the program as more focused on wanting them to 'engage in treatment' as defined by the program rather than meeting practical needs related to housing and money." Example 2: "From my experience there is no question that the degree of socioeconomic disadvantage experienced by clients has a strong impact on the likelihood that they will maintain a relationship with the program."
Influence of race, ethnicity, and culture on disengagement	Example 1: "I think that [disengagement is higher for] African American clients and families, for so many reasons. Historical oppression at the hands of government and 'treatment' centers, lack of providers that are from the community, lack of treatment modalities that are tooled specifically for communities of color almost too many reasons to list." Example 2: "The main migrant populations are Micronesian and Filipino. The Micronesian migrants suffer particularly from marginalization It's my impression that we don't even see many of these people because there are many barriers to engaging with treatment (lack of knowledge of health systems, lack of resources, differing cultural conceptualizations of psychosis)."
Intersectional impact of disadvantage and minority racial and cultural backgrounds	Example 1: "With migrants we do not have a good enough understanding of their cultures, preferences, way of life, values and they feel the disconnection because they are a visible minority [group]. They have this added stress. For our indigenous peoples that have left the reserves, they have often left situations of poverty, abuse, substance abuse and are trying to build a happy life, but they also feel that disconnection, not always having the possibility to live 'their culture and traditions.'' Example 2: 'Race and minority tratus are discussed in many stories in the news, and [clients] are taking about the discrimination they have faced. Similar to these civil rights issues are thrainaits someone is a hundre of many stories in the news, and [clients] are taking about the discrimination they have faced. Similar to these civil rights issues are thrainaitly as someone is a huge stressor and likely affects how much individuals engage in services/connect to others/feel understood." Example 3: "SES [socioeconomic status] has a huge impact on our clients and interventions. White, mainland interventions, which is rationally based on a long history of being mistory

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TABLE 4.

Providers' perceptions about emerging strategies and promising practices in early intervention in psychosis programs

Category	Quotation
Specialized services to address the trauma-related needs of ethnic minority and refugee groups	"The levels of trauma [among ethnic minority clients] also affect severity of symptoms, and we are addressing the need to improve our brain regulation skills (EMDR [eye movement desensitization and reprocessing], neurofeedback, qEEG [quantitative electroencephalogram], trauma-sensitive yoga, Capoeira Angola), so that talking therapies are more effective and medication doses can be lower. We have consortium connections to specialist culturally based services and [a specialist service for survivors of torture]."
Physically locating programs in high- need, disadvantaged neighborhoods	"We intentionally established the program in a neighborhood that would be central to several communities with high levels of poverty, disproportionately large numbers of people of color, and generally high levels of socioeconomic disadvantage."
Physically colocating with family health services	"We've also seen that family medical emergencies, possibly related to poorly controlled chronic health problems, can understandably take priority over mental health care. In order to address these possibilities, we intentionally colocated with a family services agency and a general medical practice that have served nearby communities for many years. We are therefore able to help clients meet many family needs in one trip."
Consultation with cultural, racial, and ethnic leaders or insiders	"We have an advisory panel that includes an expert in recognizing and treating trauma in communities of color and the director of a local nonprofit designed to engage communities of color in mental health treatment. Both experts have consulted extensively with me and will be working with the entire staff in the future."
Direct involvement with relevant cultural, ethnic, and racial minority communities	"Members of the clinical team frequently take part in nearby community events in order to increase our understanding of 'what matters' to the people we serve."
Explicitly addressing inequality and power hierarchies through supervision	"The supervision I provide covers issues of inequality and power, and I try to ensure (in my position as supervisor) that issues of power and inequality are adequately formulated and attended to."

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TABLE 5.

Providers' perceived challenges, concerns, and unmet needs concerning early intervention in psychosis (EIP) programs

Category	Quotation
EIP programs or models can be too one-size-fits-all	Example 1: "I have seen a lack of knowledge and a one-size-fits-all approach leading to the service not being suitable for some people and their families." Example 2: "Seeing psychosis through a mainstream lens I believe leads to misdiagnosis—overdiagnosis in some cases, underdiagnosis in others. And to treatment discontinuation. Better, clearer guidelines and training are needed for a truly culturally responsive early psychosis program."
Underlying ethnocentrism in EIP models and practice	"Most of the [privileged models] are individualized approaches that are permeated by White, Western (male) worldviews, such as CBT [cognitive-behavioral therapy] and the medical model. Moreover, as these assumptions are taken for granted, they are not adequately critiqued. It is therefore difficult to work from the perspective of the individual client/family and attend to their cultural perspectives and needs when the wider system is not supporting such practice."
Socioeconomic needs are decentered	"The model of the program does not prioritize needs related to socioeconomic disadvantage, and this means that in practical ways these needs are not adequately addressed and also that in more abstract ways these needs and experiences are disconnected from how problems are conceptualized and approached by staff. The primary focus [on therapy] at times translates into needs related to socioeconomic disadvantage being decentered and not being seen as key foci of treatment or recovery."
Providers can be ethnocentric	"We still have a long way to go before clinicians in early intervention services understand cultural humility and sensitivity. The common belief that psychosis arises from a universal illness process prevents providers from seeing culture as meaningful, and cultural beliefs and experiences are still often misrecognized as 'symptoms.' Providers are also often unaware of (or even judgmental of) indigenous explanatory models and healing practices."
Biomedical clinical frameworks are overemphasized	"There is an overemphasis on biological explanations for symptoms to [the] exclusion of a [broader] range of explanations."
Lack of and need for team diversity	Example 1: "Having staff and peer and caregiver support workers from a variety of cultural backgrounds would help." Example 2: "I think the best way to address cultural differences is to engage staff and clients from diverse cultural backgrounds when designing or improving early psychosis services."
Lack of and need for deeper engagement with clients' values, experiences, and priorities	Example 1: "Lack of knowledge and understanding of different religions (specifically Islam and Sikh) have proven to be a challenge within our clinic. It has resulted in assumptions being made that were untrue or hindered the progress of therapy, as specific recommendations or exercises were in direct contrast with a client's religious values. I think the only way to best address cultural differences is to continue to steep ourselves in the experiences of others. Asking our clients questions open dialogue about their experiences of their and religion is the only way to ensure we are understanding the ways in which these differences impact their lives. A continued open dialogue about remaining genuinely interested in understanding another person's experience may help to keep clinicians aware of their own biases and need for education." Example 2: "[I] those seem that the standardized treatment formats (such as early intervention manuals) could be expanded to better address trauma and cultural diversity. I think we need much more effort to hear from people who are in early psychosis treatment, who have been through it, and ESPECIALLY people who did not feel early psychosis was a good fit for them."
Lack of and need for meaningful engagement with cultural minority communities	Example 1: "I would like to see much more link[age] with local communities to identify problems and barriers and build roles for people within those communities to better understand how to meet [service user] needs." Example 2: "With respect to [collective] trauma—like that which is carried by entire communities—programs and clinicians need to seek out and value relationships with a range of experts from those communities, not just other clinicians. We need to look at the way in which the community expresses the effects of that trauma (artistically, religiously, medically, socially—as many ways as possible) in a serious way in order to begin to appreciate the impact of the trauma that a community might hold."
Lack of and need for meaningful engagement with cultural healers and healing practices	"[There is a] lack of knowledge on how to work effectively with—and/or a poverty of power in working with—culture healing professionals (curandera/o, hands-on healers, naturopaths)."