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Equity in Mental Health Services for Youth at Clinical High Risk for Psychosis: Considering Marginalized Identities and Stressors

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Abstract

Prevention and early intervention programs have been initiated worldwide to serve youth at Clinical High Risk for Psychosis (CHR-P), who are adolescents and young adults experiencing subclinical psychosis and functional impairment. The primary goals of these efforts are to prevent or mitigate the onset of clinical psychosis, while also treating comorbid issues. It is important to consider issues of diversity, equity, and inclusion in CHR-P work, especially as these programs continue to proliferate around the world. Further, there is a long history in psychiatry of misdiagnosing and mistreating psychosis in individuals from racial and ethnic minority groups. Although there have been significant developments in early intervention psychosis work, there is evidence that marginalized groups are underserved by current CHR-P screening and intervention efforts. These issues are compounded by the contexts of continued social marginalization and significant mental health disparities in general child/adolescent services. Within this narrative review and call to action, we use an intersectional and minority stress lens to review and discuss current issues related to equity in CHR-P services, offer evidence-based recommendations, and propose next steps. In particular, our intersectional and minority stress lenses incorporate perspectives for a range of marginalized and underserved identities related to race, ethnicity, and culture; faith; immigration status; geography/residence; gender identity; sexual orientation; socioeconomic status/class; and ability status.

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Keywords

prodrome; equity; inclusion; intersectionality; stigma

There have been worldwide efforts to identify and treat youth at Clinical High Risk for Psychosis (CHR-P), a heterogenous group of youth who experience distressing attenuated psychosis symptoms (e.g., subthreshold hallucinations, delusions, disorganization) (Catalan, Salazar de Pablo, et al., 2020; Fusar-Poli, Salazar de Pablo, et al., 2020; Kotlicka-Antczak et al., 2020). Compared to other youth clinical groups, individuals at CHR-P are at a heightened risk for developing a psychotic disorder in the future and often experience distressing comorbid psychopathology (Addington et al., 2017; Lim et al., 2015), as well as functional impairment (Fusar-Poli et al., 2013). Current estimates suggest that approximately 25% of youth at CHR-P go on to develop threshold psychosis within three years (Catalan, Salazar de Pablo, et al., 2020; Fusar-Poli, Salazar de Pablo, et al., 2020), with non-converters still demonstrating clinically significant difficulties that warrant treatment (Addington et al., 2011; Beck et al., 2019). CHR-P programs typically provide transdiagnostic treatment to meet the needs of these youth and their families, and the goals of these programs generally include preventing or delaying the transition to threshold psychosis by reducing distress and building coping skills (Thompson et al., 2015). To fully realize the goals of programs such as these, it is imperative to have equitable and culturally sensitive research and services that identify and treat diverse youth and families. Given the association between psychosis and social determinants (Anglin et al., 2020), as well as historical abuse and racial disparities related to psychosis conceptualizations and diagnoses (Loring & Powell, 1988; Metzl, 2010; Nazroo et al., 2020; Schwartz & Blankenship, 2014), it is especially important to consider issues of diversity, equity, and inclusion in CHR-P work.

Contexts

Research and Policy Context

CHR-P programs are proliferating worldwide (Catalan, Salazar de Pablo, et al., 2020; Fusar-Poli et al., 2017; Kotlicka-Antczak et al., 2020). Just in the United States (US), the Substance Abuse and Mental Health Services Administration (SAMHSA, 2018) recently funded more than 20 CHR-P low-cost treatment programs in the past three years, and the National Institute of Mental Health (NIMH, 2020) recently partnered with multiple worldwide agencies to support a collaborative effort to advance CHR-P research. This large-scale NIMH project, the *Accelerating Medicines Partnership for those at risk of developing Schizophrenia*, will include research on biological and psychosocial factors related to disease progression, with aims of better understanding CHR-P trajectories and informing treatments. Additionally, worldwide and cross-cultural CHR-P work is ongoing elsewhere, including work focused on improving detection, identifying biological correlates, and implementing services (Zhang et al., 2020).

Broader Social Context

These promising services and research endeavors come at a time when social inequities have become amplified for many marginalized groups due to the global COVID-19 pandemic and rising racially and ethnically motivated terrorism (e.g., white supremacist terrorism) (Laster Pirtle, 2020; State, 2019). Residual health impacts are expected for racial and ethnic minority (REM) groups (Novacek et al., 2020), and the effects of the current social context have also already negatively impacted—or have been predicted to impact—people at CHR-P or those experiencing threshold psychosis or other serious mental illness (Cowan, 2020; DeLuca et al., 2020; Nemani et al., 2021). These issues are compounded by the context of significant mental health disparities in general child/adolescent health services (Merikangas et al., 2011; Whitney & Peterson, 2019), which may prevent or delay the identification of young people at CHR-P since many CHR-P referrals come from general outpatient and inpatient psychiatric departments (Cornblatt, 2002; Fusar-Poli et al., 2016).

Social Inequities and CHR-P Experiences

Research has documented that social inequities and CHR-P experiences are intertwined (Anglin et al., 2020). For example, high neighborhood crime has been related to high suspiciousness among individuals at CHR-P (Vargas et al., 2020; Wilson et al., 2016). Psychotic experiences, which conceptually overlap with the CHR-P state, have also been associated with police victimization (DeVylder et al., 2017), racial discrimination (Anglin et al., 2014; Oh et al., 2016), other trauma exposure (Mayo et al., 2017; Redman et al., 2017), and urbanicity and air pollution exposure (Newbury et al., 2019). In general, REM individuals have been found to endorse higher levels of subclinical psychosis experiences (Calkins et al., 2014; Morgan et al., 2009; Wigman et al., 2011), as well as potentially unique symptom presentations that intersect with discrimination and trauma (Anglin et al., 2015; Thompson et al., 2009). More broadly, components of inequality (e.g., income inequality) have been associated with a higher schizophrenia incidence worldwide (Boydell et al., 2004; Burns et al., 2014). Further, lack of involvement of REM youth in early intervention CHR-P programs may have negative long-term, downstream effects, such as delayed mental health diagnosis and disproportionate criminal justice system involvement (Al-Rousan et al., 2017; Youman et al., 2010).

Successes and Limitations of Current CHR-P Programs

These findings suggest that there is likely an even greater need for psychosis prevention work and specialized CHR-P research programs and services among marginalized groups. Notwithstanding the major successes of CHR-P programs (i.e., worldwide hubs of research and clinical experts who improve the lives of youth and families) (McGorry et al., 2021), youth may be hesitant to seek and engage in CHR-P services (Ben-David et al., 2019a; Ben-David et al., 2019b; Leanza et al., 2020) and there is evidence that marginalized groups are underserved by current early-stage psychosis prevention screening, intervention, and research efforts (Anglin et al., 2020; Deriu et al., 2018; Oluwoye et al., 2021). This raises major questions regarding outreach to, and identification of, marginalized groups for psychosis prevention. In particular, although the reliability and validity of semi-structured assessments have been found to be generally consistent across countries, more research is needed overall (Woods et al., 2019), including research on cultural group differences in the same country. To this end, mixed results have been found regarding the precision of common CHR-P screening tools for REM youth in the US (Cicero et al., 2019; Karcher et al., 2018; Lång et al., 2020; Millman et al., 2019; Rakhshan Rouhakhtar et al., 2019), which may contribute to inequity since screening tools are generally the first line of assessment to determine potential psychosis risk and further inclusion in research studies and services.

Research has also demonstrated that REM youth are less likely to visit specialized psychosis services (compared to non-Hispanic White youth) before their first presentation of psychosis (Coleman et al., 2019), suggesting that culturally sensitive outreach to these groups may be particularly warranted (Lynch et al., 2016). Additionally, research on first-episode psychosis (FEP) service use—which the CHR-P state may be a precursor to—has also demonstrated racial disparities, namely that Black youth (compared to White youth) are more likely to experience homelessness and housing insecurity, to have a significantly poorer quality of life, exhibit more severe symptoms, and are less likely to have private insurance (Nagendra et al., 2018). Non-Hispanic Black youth in FEP programs have also been found to be less likely to receive important early intervention services, such as family psychoeducation (Oluwoye et al., 2018). Overall, results from FEP studies on disparities strengthen the premise that increasing equity in CHR-P services may be one upstream method to reduce disparities in FEP programs.

Our Framework

The framework of this narrative review and call to action is based on minority stress models (Brooks, 1981; Meyer, 2003) and intersectional models (Crenshaw, 1989; Seng et al., 2012) of mental health, and thus acknowledges that understanding and focusing on stressors affecting marginalized groups and those of oppressed identities are paramount to increasing equity in CHR-P services. For presentation clarity, we describe various identities separately below while acknowledging that intersectionality is a process by which multiple oppressed identities *interact* and *combine* to increase inequity and stress. We note some of these interactions and nuances within each section, as well as in our Discussion section. The intersectional identities below were chosen based on foundational past minority stress and intersectional research (Crenshaw, 1990; Hays, 1996), including emerging research with individuals at CHR-P (Ruiz et al., 2021; Saleem et al., 2014). These identities include developmental stage and associated factors; race, ethnicity, and culture; faith; immigration status; geography/residence; gender identity; sexual orientation; socioeconomic status/class; and ability status. We tie together these identities in a concluding section on minority stress and trauma, acknowledging the high prevalence and confluence of various stressors that further perpetuate disparities.

Method

We adopted a narrative review and call to action approach for this work, similar to other recently published early-stage psychosis articles focused on exploring distinct literatures and generating empirically-based recommendations (Brooke et al., 2019; Harrop et al., 2015). Building on our interest in reviewing a broad range of CHR-P equity issues using an intersectional and minority stress lens, we believed that a narrative review and call to action approach would be most appropriate. Some authors have referred to this approach as a critical review that allows one to "take stock" of and synthesize broad work in the field, while fostering "conceptual innovation" to help move the field forward (Brooke et al., 2019; Grant & Booth, 2009). Our search terms included CHR-P and related terms, terms related to the various identities discussed above (Crenshaw, 1990; Hays, 1996), and terms including and related to diversity, equity, and inclusion. Snowballing techniques were used by searching the reference lists of relevant articles. All searches were conducted in February and March 2021.

Below, we provide the results of our narrative review organized by intersectional identity, with a concluding section on the overlap of trauma and stressful life experiences across these identities. We then provide our recommendations and "call to action" based on this review, followed by a discussion and conclusion.

Results

Developmental Stage and Associated Factors

As noted, CHR-P experiences typically first occur during adolescence and young adulthood, which are key developmental periods. During this time, youth are contending with significant psychological, social, and biological/physical changes. Youth at CHR-P present to different clinics (e.g., child/pediatric v. adult) and with different presenting concerns and current life problems, depending on their age and developmental stage. For example, research has found that younger youth (~age 13 and younger) endorse more items on psychosis-risk screening tools compared to older youth (Rouhakhtar et al., 2019), which may increase the false-positive rate for this group. Nonetheless, early identification of true psychotic experiences among younger teens (~age 11-12) may signal vulnerability for future psychopathology (Rimvall et al., 2020). In general, researchers have called for a careful evaluation of psychosis-risk experiences in the context of normative developmental experiences (Carol & Mittal, 2015; Schiffman et al., 2019). In regard to developmental milestones, psychosis risk experiences have also been positively associated with developmental delays in speech and motor skills (Karcher et al., 2018), as well as various, early neurocognitive delays (Gur et al., 2014), highlighting the importance of a detailed intake and collaboration with collaterals (e.g., caregivers) for historical information.

From a psychological perspective, adolescence and young adulthood are key periods of identity development (Erikson, 1968), and researchers are only just beginning to understand the potentially unique process of identity development for youth at CHR-P (Ben-David & Kealy, 2020; Sarac et al., 2021). In terms of cognitive development, researchers have also shed light on cognitive biases that may be more prevalent among youth at CHR-P, such as jumping to conclusions (Catalan, Tognin, et al., 2020). These factors can directly inform assessment and treatment strategies.

From a biological and neurobiological perspective, several developmental mechanisms have also been proposed, including the role of hormones in modulating brain development for individuals at CHR-P (Corcoran et al., 2003; Damme et al., 2020; Trotman et al., 2013; Walker, Trotman, Goulding, et al., 2013). One recent study (Damme et al., 2020) reported that early exposure to estrogens (i.e., earlier age at menarche) may have a protective impact on hippocampal connectivity for youth at CHR-P, highlighting the importance of considering developmental factors during evaluation, treatment, and research. As will be noted in a later section, this finding may also have implications for equity in early psychosis services for women, a group that also tends to have a later onset of psychotic experiences (Ferrara & Srihari, 2021). Lastly, biological changes also trigger physical changes for youth, and youth at CHR-P have been found to perceive more discrimination related to their "appearance" than a non-clinical sample (Saleem et al., 2014).

From a social-contextual perspective, most youth at CHR-P live with their families (Addington et al., 2015), and studies have found that stronger youth-reported family functioning (e.g., cohesion, support) may be a protective factor for youth at CHR-P (Izon et al., 2018; Izon et al., 2021; Thompson et al., 2019; Wüsten & Lincoln, 2017). Further, poorer caregiver-reported family functioning has been associated with higher perceived discrimination experiences among youth with psychosis-spectrum symptoms (DeLuca et al., 2021). Research has also found that stigma among families may be an important variable to consider for youth at CHR-P (Colizzi et al., 2020; Wong et al., 2009). In particular, one of these studies (Wong et al., 2009) found that only REM families (of individuals with recent, full psychosis) endorsed feeling shame and a need to conceal their family member's illness. Thus, outreach and interventions focused on engaging families of youth at CHR-P (particularly REM families) and building coping skills in a culturally sensitive manner appear to be important endeavors (Gerson et al., 2011; Santesteban-Echarri et al., 2018). Further, given the high rate of general social functioning deficits among youth at CHR-P (Cornblatt et al., 2007; Velthorst et al., 2010), as well as high rates of childhood bullying victimization (Mayo et al., 2017), multipronged and transdiagnostic efforts focused on these factors may also be warranted.

Race, Ethnicity, and Culture

From the prenatal period through childhood, it is well-established that the rate of exposure to many of the risk factors for psychosis (e g., poor prenatal care, trauma, stress, discrimination) is much higher for REM than White youth (Dunkel Schetter et al., 2013). Despite this, REM youth are less likely to receive mental health services compared to White youth (Kataoka et al., 2002). In one of the largest studies conducted to date on adolescent mental health service utilization (Merikangas et al., 2011)—using a US national sample of over 6,000 adolescents and structured interviews to determine mental health diagnoses—it was found that Hispanic and non-Hispanic Black adolescents were significantly less likely to receive services (compared to White adolescents), specifically for mood and anxiety disorders. This is particularly notable in regard to equity in CHR-P services, because anxiety and mood disorders often precede or co-occur with attenuated psychotic symptoms among youth at CHR-P (Addington et al., 2017; Lim et al., 2015) and symptoms related to these disorders may be the first presenting problems for youth considering treatment.

The barriers to care that REM youth experience are often structural and a product of marginalization. REM youth are more likely to be uninsured or underinsured, thus creating financial obstacles to accessing needed mental health services (Kataoka et al., 2002). However, barriers to mental health services are not solely financial; a recent study with youth experiencing FEP found that racial/ethnic disparities in diagnosis and treatment may be present even for insured youth and after controlling for household income (Heun-Johnson et al., 2021).

There are also significant cultural differences in how REM individuals perceive mental health concerns, pathways to mental health services, and help-seeking preferences (Cauce et al., 2002). REM families may have different interpretive frameworks for mental health experiences, such as spiritual or religious explanations (Esterberg & Compton, 2006) that can impact CHR-P help-seeking. REM individuals often seek out non-medical support to deal with emotional concerns such as pastors or religious clergy, family, and friends (Cauce et al., 2002; Novacek et al., 2019). In addition, REM youth often experience aversive pathways to mental health through justice system involvement and involuntary hospital admissions (Compton et al., 2006). REM youth may also have difficulty accessing mental health care services due to the lack of culturally competent providers in their area. In addition, many CHR-P clinics are housed within academic medical centers that often do not serve REM youth. Among Black Americans, there is a skepticism or cultural mistrust of healthcare including mental health services due to medical racism (Whaley, 2001a, 2001b). Given that many CHR-P services are housed within academic medical centers, this distrust, along with “ivory tower” and inaccessibility perceptions, could prevent youth from seeking care (Lynch et al., 2016). Research also demonstrates that REM individuals often hold more stigmatizing beliefs about mental illness and mental health treatment compared to White Americans (Brown et al., 2010; DeFreitas et al., 2018). These stigmatizing attitudes could deter REM youth from seeking and adhering to mental health services.

Faith

Faith, spirituality, and religious beliefs often serve as an integral coping strategy and as protective factors against suicide (Koenig, 2009). However, a double-edge sword is possible in that religious interpretations of legitimate attenuated psychotic experiences could delay treatment seeking. On the other end, clinicians must be cautious of pathologizing religious beliefs without considering how normative the experiences are within an individual’s faith community (O’Connor & Vandenberg; Pierre, 2001). Very little research to date has been conducted on faith and CHR-P, but emerging research in this area suggests that there may be a relation between religiosity and depressive symptomology (Severaid et al., 2019) and religiosity and perceptual abnormalities/hallucinations (Loch et al., 2019) for youth at CHR-P. Loch et al. (2019) also found relations between religiosity and other attenuated experiences (ideational richness, suspiciousness) that require further research. In an earlier study, it was also found that families of patients at CHR-P or in the early stages of a psychotic disorder used religious coping (i.e., seeking God’s help, trying to find comfort in religion, praying) at a moderate level (Gerson et al., 2011), highlighting the importance of considering broader family coping strategies.

Immigration Status

An individual's status as an immigrant may also play an important role in their risk for psychosis and decision or ability to engage in CHR-P services. Research has consistently shown that the incidence of psychosis is higher among refugee and nonrefugee migrant populations compared to native populations (Brandt et al., 2019; Cantor-Graae & Selten, 2005). Research also shows that increased incidence of psychosis for second-generation migrants is comparable to first-generation migrants (Bourque et al., 2011; Weiser et al., 2008), suggesting potential intergenerational transmission of trauma related to migration. It has been suggested that this risk for second-generation migrants may reflect stress within the new country (e.g., discrimination, social exclusion) rather than migration-specific stressors (Henssler et al., 2020), but this effect for second-generation immigrants has not been found in some studies (Corcoran et al., 2009b).

Although there is a wealth of research demonstrating increased risk for psychosis among migrants, there is minimal research on CHR-P migrants. Thus far, researchers have not demonstrated an association between migrant status and transition to psychosis among individuals at CHR-P (Geros et al., 2020; O'Donoghue et al., 2021). However, studies show that duration of untreated psychosis is significantly longer in migrants (Boonstra et al., 2012), indicating that migrants are not being identified early on in the CHR-P state and are thus less likely to receive the benefits of early intervention.

The proposed pathways by which migration may contribute to increased risk for psychosis emphasizes the compounding effect of post-migratory stress, trauma-related factors, social isolation, difficulties re-entering society, stigma/discrimination, family dysfunction, poverty, and poor housing conditions (Henssler et al., 2020; Veling & Susser, 2011). Individuals at CHR-P with a migration history have also shown more severe symptoms, including significantly more formal thought disturbances and sleeping problems compared to those without a migration history (Nogueira et al., 2020). In addition to social and societal challenges, neurochemical changes in the brain of CHR-P migrants may increase risk of psychotic symptoms. In independent CHR-P samples from the United Kingdom and Canada, striatal dopamine function was elevated in immigrants compared with natives (Egerton et al., 2017), which is consistent with findings among individuals who have already developed a psychotic disorder (Henssler et al., 2020). It has been suggested that these neurochemical changes may be caused by psychosocial factors such as victimization, discrimination, social exclusion, and other social and environmental factors (Egerton et al., 2017).

In a study of providers' impressions of the disadvantages experienced by minority groups in early intervention for psychosis services, providers noted higher rates of family disengagement among recent immigrants and those with a history of marginalization (Jones, Kamens, et al., 2021b). Providers indicated that this may be due to limited knowledge about mental health system and lack of resources. The location of CHR-P programs also matters for migrants. In a prospective population-based study, low neighborhood ethnic density (proportion of ethnic minorities in an area) at age 15 was associated with increased incidence of psychosis for migrants, even after controlling for urbanicity, parental SES, and parental psychiatric history (Schofield et al., 2017). This suggests that living in a higher ethnically dense neighborhood may reduce social stress, and thus highlights the importance of moving care into migrant neighborhoods.

Stigma may present another barrier to mental health treatment for migrants. There is evidence to suggest that the incidence of psychosis is higher when immigrant groups perceive more racial/ethnic discrimination (Veling et al., 2007), and that discrimination may serve as a mediator for psychotic symptom severity in immigrants (Berg et al., 2011). However, unlike studies in psychosis, one study using a CHR-P sample did *not* find associations between immigration status and perceived discrimination (Saleem et al., 2014). More research is needed to understand stigma among youth at CHR-P with a personal or family history of migration.

Geography/Residence

Epidemiological and cohort studies reliably demonstrate that exposure to urban environments is associated with increased risk for psychosis. Risk increases as level of urban exposure increases in a dose-response manner (Pedersen & Mortensen, 2001a), leading many to conclude that urbanicity is an environmental cause of psychosis (Krabbendam & van Os, 2005). This finding is consistent across varied definitions of urbanicity, and holds up strongly when assessing for other important demographic and environmental factors such as age, sex, ethnicity, substance use, social class, genetic risk, distance to hospital, use of mental health services, and countless others (Krabbendam & van Os, 2005; Lewis et al., 1992; McGrath et al., 2004; Pedersen & Mortensen, 2001b; Spauwen et al., 2004; Stefanis et al., 2004). However, this effect may not be present in developing countries (DeVylder et al., 2018).

Urbanicity has been associated with both positive and negative symptoms of psychosis (van Os et al., 2002), and with psychosis-like symptoms, which are more prevalent in the population than psychotic disorders (van Os et al., 2001). The relationship between urbanicity and incidence for schizophrenia suggests some unique environmental impact of urban areas that likely exerts its influence during child and adolescent development rather than close to illness onset (Marcelis et al., 1999; Pedersen & Mortensen, 2001a). What this means for CHR-P youth is that the earlier that psychosis risk symptoms can be identified and treated, the more likely it is that providers can impart protective factors that counter such environmental risk factors.

Research specifically on individuals in the early stages of psychosis or at CHR-P demonstrates the potential adverse impact of urbanicity on important outcomes. In a prospective study of Individuals at CHR-P, urbanicity was among the predictors for transition to psychosis (Dragt et al., 2011). In a study of FEP patients from rural and urban areas, duration of untreated psychosis was significantly longer for individuals from highly urbanized areas (and first-generation immigrants, as noted above) (Boonstra et al., 2012).

Aspects of rural living may also impact risk for psychosis. In a study looking only within rural environments (e.g., consisting of dispersed farms, villages, small towns), higher prevalence of psychotic disorder was associated with material deprivation (i.e., a single measure that combines information regarding unemployment, housing, car ownership, etc.)

(Omer et al., 2014). Similarly, in a population-based study of FEP individuals in rural environments, there was a higher incidence of psychosis in more deprived and socially isolated areas (Richardson et al., 2018). Rural youth at CHR-P also have different help-seeking behaviors compared to urban youth and have greater functional impairment (Stain et al., 2018).

For individuals at CHR-P, social isolation and material deprivation (e.g., lack of car, lack of internet access in the home) may present barriers to seeking and accessing care during the onset of psychotic like symptoms, and indeed one study showed a trend for individuals at CHR-P to reside in relatively more deprived areas (O'Donoghue et al., 2015). Rural youth often must travel longer distances to receive care, and there is less access to specialized CHR-P programs in rural compared to urban areas (Stain et al., 2018). Overall, there is minimal research regarding the specific needs of rural youth and service delivery in rural areas (Welch & Welch, 2007). Lastly, beyond rural and urban environments, there is evidence in the US that there are major quality and racial-ethnic disparities in psychosis-spectrum care depending on which county you live in (Horvitz-Lennon et al., 2015).

Gender Identity

In discussing what is known regarding the role of gender identity in CHR-P, it is important to note that much of our understanding of these risk states and of the illness and treatment of schizophrenia is based on research conducted disproportionately with men and virtually all within binary gender categories or by biological sex, which conflates gender and sex and does not as readily account for environmental factors that may influence people of different genders quite differently. Indeed, meta-analyses of epidemiological and non-epidemiological research conclude that while expected epidemiological incidence rate was 58% male, on average, males comprise over two-thirds of study samples of schizophrenia (Longenecker et al., 2010). While CHR-P recruitment often involves rigorous case finding, meta-analyses on gender differences in symptoms and functioning similarly include mostly males (Tor et al., 2018), with only about one-third of participants categorized as binary female (Rietschel et al., 2017). In light of this, our understanding of etiology, symptom expression and associations, and resulting treatment recommendations may not fully reflect or apply to the experiences of CHR-P youth who do not identify as male-gendered.

Further, the overproportion of identified male-gendered participants may indicate gendered barriers, such as under-identification by referral pathways due to schema, to entrance to treatment settings where such clinical research is conducted. Indeed, compared with men, literature suggests that women tend to present with more mood symptoms which may lead to misdiagnosis of psychosis due to primary affective disorder, often an exclusion criterion for research-based FEP services (Heitz et al., 2019; Ochoa et al., 2012). Additionally, CHR-P clinics may narrow eligible age range to transition-aged-youth, excluding individuals whose biological female sex is associated with later onset (median first contact age 34 for female vs 28 for men) (Ferrara & Srihari, 2021). No gender differences have been found in conversion rates of CHR-P youth across longitudinal follow up (Walder et al., 2013), or within epidemiological studies (Scott et al., 2006). Delays in receiving care due to misdiagnosis or missed identification may lead to longer duration of untreated psychosis, a predictor for poorer outcomes.

There may also be strengths associated with the differential gender socialization of individuals. For example, it may be more acceptable for individuals socialized as women to disclose experiences, seek help (Mackenzie et al., 2006), or rely on social networks and support (Willhite et al., 2008). Poorer baseline social functioning and positive prodromal symptoms have been shown to predict greater conversion risk in men (Walder et al., 2013).

There remains a scarcity of literature on clinical care for transgender and gender expansive populations with serious mental illness (Barr et al., 2021; Meijer et al., 2017; Mizock & Fleming, 2011). They may avoid participation in such environments due to perceived burden to educate (Lucksted, 2004), transphobic rejection (Rossman et al., 2017; Smith et al., 2019), and historically founded concerns of misjudgment of gender identity as a symptom of psychosis (Hoenig & Kenna, 1974) or intervention targets (Mizock, 2008). Preliminary evidence from recent initial explorations demonstrates that many gender-expansive youth do not disclose their gender identity to all of their health care providers, though positive associations are found between disclosure and self-esteem (McKay & Watson, 2020). Previous work demonstrates disclosure as an important protective factor from all psychiatric disorders (Dhejne et al., 2016). Social signaling, such as use of binary categories of gender within care settings and failure to glean specific knowledge of various genders within research explorations or clinic intake, may further this chasm within CHR-P populations.

Given markedly greater relative risk demonstrated for comorbid depression, anxiety and suicidal ideation among gender expansive compared to cisgender youth (Day et al., 2017; Reisner et al., 2015), targeted treatment may be particularly effective, as reduction of mood symptoms alone has demonstrated improvement in CHR-P prognosis (Thompson et al., 2015; van der Gaag et al., 2013). Further, adolescent and transition-age individuals who present to CHR-P clinics may be in the process of discovering gender identity at the time of presentation or may be fluid in presentation over time. As disruption and loss of sense of self are increasingly implicated in schizophrenia spectrum experiences (Ferri et al., 2014), affirmation of presenting identity may be particularly crucial for youth at risk for psychosis in self-integration to reduce a potential predisposition that incongruent treatment may exacerbate.

Sexual Orientation

Not to be conflated with gender identity, consideration of sexual orientation may be an additional important facet in conceptualization and treatment for individuals at CHR-P. Large scale studies indicate an up to three-fold increased risk of psychotic experiences for queer as compared to heterosexual individuals, that may be partially mediated by experience of discrimination, stress, and lack of social support related to sexual orientation (Bolton & Sareen, 2011; Chakraborty et al., 2011; Gevonden et al., 2014; Jacob et al., 2021). Most recently, when accounting for additional sociodemographic factors including sex, age, and ethnicity, a two-fold risk remained (Jacob et al., 2021). Particularly, loneliness has been robustly associated with increased risk of psychosis (Michalska da Rocha et al., 2018) and endorsed commonly in addition to lack of social support amongst queer individuals

(Doyle & Molix, 2016). Some evidence suggests that particular psychotic experiences such as paranoia or mania, rather than hallucinations, may be more prominent for LGBT+ individuals (Jacob et al., 2021; Janssen et al., 2003), supporting a hypothesis that adversity may have specific effects on psychotic experiences which differ in etiology and may not otherwise develop.

Data demonstrates a growing imperative for attention and care to sexual orientation diversity. In 2020, an estimated 1 in 6 transition-aged youth surveyed in the United States identified as LGBT+ (Gallup, 2020), continuing a rising trend in such identification since tracking began in 2012, without accounting for response-bias due to stigma. Estimates of US adolescent populations indicate greater variance in orientation, with about 20-25% of youth in grades 9-12 identifying as LGBT in 2019, according to the CDC (Health, 2019). However, only 1 in 3 LGBT+ adolescents report disclosure of orientation to medical providers due to realistic concerns of stigma, discrimination, or lack of inquiry from providers (Rossman et al., 2017).

Socioeconomic Status/Class

Another social and environmental risk factor for psychosis that may contribute to inequity in CHR-P identification and treatment is socioeconomic status (SES). An individual's SES can be measured in a variety of ways, but is typically measured as household income or education level, as higher levels of education are associated with better economic outcomes and resources. Neighborhood level economic factors, such as neighborhood poverty level, neighborhood crime, or the ranking of a school system, have also been assessed as a proxy for SES. In a systematic review and meta-analysis, lower SES was significantly associated with higher incidence of psychosis (Castillejos et al., 2018) and income inequality has also been associated with increased incidence of schizophrenia (Burns et al., 2014). The impact of SES on incidence of psychosis has been found to be most detrimental for offspring of fathers in the lowest social class (i.e., paternal occupation at time of birth) (Corcoran et al., 2009a). There is also the risk of low SES driving public stigma toward the individual. In an online study of 1,348 adult volunteers, both "uneducated people" and "mentally ill people" elicited negative appraisals of incompetence and abnormality, suggesting a strong bias against individuals with lower formal education and SES (Phelan et al., 2019).

Ability Status

An important consideration regarding equity and access to CHR-P services includes ability status. Ability status refers to differences in intellectual, physical, social, or emotional domains that may or may not present visibly (e.g., use of a wheelchair, speech impediment, major psychological or neurological condition, etc.), and which may be temporary or permanent and dependent on context (Nielsen, 2012). Ableism continues to display and detract from mental health care, through lack of attempts toward inclusion such as physically accessible space, organization and visualization of written documents, infrequent provision of close captioning and use of language depicting individuals as "high or low functioning" based on neurodivergence (Cornwall, 2020). As technology evolves, opportunities for access expand and must be creatively adapted.

Very few studies have been published in the psychosis field on ability status, and the majority of studies published on “disability” and psychosis-risk refer to psychosocial disability (e.g., greater difficulty making or maintaining friendships or joining community activities) (Olvet et al., 2015; Velthorst et al., 2010). Individuals at CHR-P are generally aware of such functional impairment and this awareness is associated with depression (Olvet et al., 2015). Neurocognitive deficits are also well-documented among youth at CHR-P and can directly impact functioning (Carrión et al., 2011). Overall, it is plausible that early intervention psychosis efforts may help to prevent long-term functional (e.g., social and role) disability.

One study has assessed physical disability among youth at CHR-P and found no association between physical difficulties (e.g., moving and getting around) and transition to psychosis (Velthorst et al., 2010). Another study assessed physical disability among a broader group of people with “psychotic experiences” (Oh et al., 2018) and found that individuals who reported a disability (including mobility disabilities) had a 1.5-3x higher chance of reporting lifetime psychotic experiences, even after adjusting for socio-demographics, lifetime mental illness, and lifetime chronic health conditions. In sum, more research is needed in this area, and it may be helpful to partner with other medical clinics/programs. Epidemiological studies, for example, have found that psychosis may be 2-3x higher among young individuals with multiple sclerosis (which can involve physical disability), compared to the general population (Patten et al., 2005). Other potential groups to be considered within this domain may include individuals with intellectual disabilities and individuals with Autism Spectrum Disorder (Cooper et al., 2007; Foss-Feig et al., 2019).

Minority Stress and Trauma

As noted, it is important to emphasize that trauma and stressors are common among individuals at youth at CHR-P (Bardol et al., 2020; Colizzi et al., 2020; Kraan et al., 2015; Loewy et al., 2019; Mayo et al., 2017; Redman et al., 2017; Stowkowy et al., 2016), particularly for those with marginalized identities (Anglin et al., 2021; Anglin et al., 2014; Anglin et al., 2018; Anglin et al., 2015; Saleem et al., 2014). Based on aforementioned minority stress models (Brooks, 1981; Meyer, 2003), individuals who possess minoritized identities face tremendous, often cumulative, stigma-related stressors and traumas, which confer risk for psychopathology. Thus, it is particularly important to be aware of how these factors impact youth at CHR-P.

Our review revealed that discrimination (toward various marginalized identities) is associated with psychotic symptoms (Janssen et al., 2003; Pearce et al., 2019) and is a significant predictor of the conversion to psychosis in CHR-P youth (Colizzi et al., 2020; Stowkowy et al., 2016). In addition to the aforementioned social inequalities, including studies on the positive association between neighborhood crime and CHR-P (e.g., Vargas et al., 2020; Wilson et al., 2016), community studies have also documented associations between direct exposure to community violence and psychotic experiences (Rakhshan Rouhakhtar et al., 2019). CHR-P studies have also shown that trauma exposure is significantly associated with severity of attenuated positive symptoms, specifically among REM patients (Thompson et al., 2009). Such stress and trauma has been found to “get under the skin" of youth at CHR-P, with research demonstrating that greater exposure to deprivation, such as poverty and neglect, is associated with smaller cortical volume and smaller right hippocampal volume in a CHR-P sample (LoPilato et al., 2019). To this end, researchers have also proposed that the diathesis-stress model can be used to understand the impact of stressors on individuals at CHR-P, with the biological effects of stress being mediated by the hypothalamic-pituitary-adrenal axis (Corcoran et al., 2012; Corcoran et al., 2003; Walker, Trotman, Pearce, et al., 2013).

Call to Action: Recommendations

Our recommendations (see supplemental online material) are based on the narrative review conducted and include evidence-based suggestions based on empirical research and future directions guided by identified gaps in CHR-P work. We separated some of these recommendations by identity status to draw attention to specific concerns within categories, while also providing overarching recommendations to improve equity that apply across identity status. Though not an exhaustive list, we believe that these recommendations can increase awareness of equity issues in CHR-P work and, most importantly, contribute to the development of a more equitable early-stage psychosis system of care. We offer wide-ranging recommendations covering clinical care, research, training, outreach, and policy/systemic factors, some of which have been offered by leading scholars in the field (Anglin et al., 2021; Anglin et al., 2020; Carol & Mittal, 2015; Chapman, 2020; Cornwall, 2020; Deriu et al., 2018; Fusar-Poli, de Pablo, et al., 2020; Gara et al., 2012; Hall et al., 2021; Hankerson et al., 2018; Jones, Atterbury, et al., 2021; Jones, Kamens, et al., 2021a; Kline et al., 2019; Li, Friedman-Yakoobian, et al., 2019; Li, Shapiro, et al., 2019; McGorry et al., 2019; Meijer et al., 2017; Meyer et al., 2020; Mizock & Fleming, 2011; Novacek et al., 2019; Oluwoye et al., 2021; Ozer et al., 2020; Schiffman et al., 2019; Smith et al., 2019)[1] and some of which we have developed after synthesizing the findings of this narrative review and call to action.

Discussion

Worldwide, there continues to be a significant focus on identifying and providing treatment to youth at CHR-P and their families. To fully realize the goal of preventing or delaying the onset of psychosis, it is imperative to have accessible, equitable, and personalized services that address the needs of diverse youth and families. As noted, there is a long history of abuse and racism in psychiatry toward REM groups, culminating in understandable mistrust toward institutions and groups that provide CHR-P services and conduct CHR-P research. The current research, policy, and social climates make it clear that inclusive CHR-P services should be a priority. The work of current CHR-P programs highlights a major success in early intervention in psychiatry; CHR-P programs have proliferated over the past few decades and have provided much-needed services and expertise to youth, families, and professionals. At the same time, there are critical gaps identified by the literature regarding equitable care and there is room for improvement. Throughout this narrative review and call to action, we highlighted critical intersections in this work and provided recommendations

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[1] Although not exhaustive, several examples are provided here of published work with explicit recommendations, in addition to the many other articles referenced throughout this paper.

for future work in this area – some recommendations specific to an identity, and others more general. Practitioners must be ready to initiate and respond to such conversations throughout the treatment process, and to adapt to family needs and preferences.

Overall, our current call to action took the form of a narrative review of various identities that warrant clinical consideration in the assessment and treatment CHR-P youth. To our knowledge, this was one of the first attempts to comprehensively discuss considerations for historically marginalized and oppressed groups to help promote equity in CHR-P research and services. Although we discussed issues relevant for many aspects of identity, additional research is needed to have a more nuanced understanding how to improve services for youth in which these identities intersect to create unique challenges (e.g., LGBTQ+ REM youth). As research grows in this area, future studies may also wish to use systematic reviews and/or meta-analyses to more accurately define and quantify inequity in CHR-P services, and perhaps prioritize needs for the field moving forward.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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