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The Duration of Untreated Psychosis: A Phenomenological Study

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Abstract

Mounting evidence has indicated that early intervention leads to improved clinical and functional outcomes for young persons experiencing recent onset psychosis. As part of a large early detection campaign, the present study aimed to investigate subjective experiences during the duration of untreated psychosis (DUP), or time between psychosis onset and treatment contact. Participants were 10 young adults participating in early intervention services for psychosis. After DUP was estimated during standardized baseline assessment, participants engaged in qualitative interviews focused on their life experiences prior to treatment and leading up to the present. Mixed methods data analyses compared standardized DUP estimates with participants' subjective narratives. Findings revealed that participants experienced and conceptualized a longer trajectory of subjective difficulties (TSD) beginning before and extending beyond standardized DUP estimates. Participants emphasized striving for independence and social belonging. The majority of participants reported benefiting from their current services and believed that earlier support of some kind would have been beneficial. These findings support previous research on subjective barriers to early detection and treatment seeking in young adults experiencing psychosis. Implications and future research directions include further efforts to differentiate the struggles unique to early psychosis from psychosocial risk factors and other challenges of young adulthood.

Keywords

Early intervention; duration of untreated psychosis; first episode psychosis; phenomenology; transition-age youth

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Disclosure of Interest

The authors report no conflict of interest.

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Arising out of the global early intervention movement in mental health, early intervention services (EIS) for the treatment of psychosis are a burgeoning specialty area. One aim of EIS is to reduce the ‘duration of untreated illness’ (DUI, or time between onset of prodromal syndromes and treatment), and more specifically the ‘duration of untreated psychosis’ (DUP, or time between onset of psychosis and treatment). Shorter DUP is associated with several indices of clinical and functional recovery, including decreases in negative symptom severity and higher recovery rates at 10 years (Hegelstad et al., 2012; Kane et al., 2016). However, the lived experiences during DUP that may contribute to delays in treatment seeking are poorly understood (e.g., MacDonald, Fainman-Adelman, Anderson, & Iyer, 2018). Moreover, previous studies have used varied definitions of DUP, reflecting a broader heterogeneity in operational definitions of first-episode psychosis (Breitborde, Srihari, & Woods, 2009).

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The extant qualitative research on the experiences of service users prior to entering treatment is promising but sparse. Previous qualitative studies and first-person accounts of first episode psychosis (FEP) have indicated that fear of stigma, lack of knowledge about services, and symptom normalization are barriers to treatment seeking (Allan, 2017; Cabassa et al., 2018; Ferrari, 2015; Jansen, Pedersen, Hastrup, Haahr, & Simonsen, 2015; Jansen, Wøldike, Haahr, & Simonsen, 2015; Tanskanen et al., 2011). Schalkwyk, Davidson, and Srihari (2015) found that FEP service users experienced a disconnect between their everyday concerns and initial treatment. Previous research has also suggested that pathways to care (PtC) that are experienced as distressing and/or coercive (“negative PtC”), such as emergency services or jail/prison, can affect initial engagement (Bhugra et al., 2004; Morgan et al., 2004).

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Other qualitative studies have illuminated reasons for treatment delays during DUP from the perspectives of family members. For example, Bergner et al. (2008) identified four themes related to treatment delay: (1) misattribution of symptoms to another mental disorder or acute stress response, (2) treatment sought only in response to extreme distress, (3) views that the person was autonomous and capable, and (4) systems-level factors such as availability of affordable services. Similarly, in an interview study of African American family members’ views about stigma and treatment initiation in FEP (Franz et al., 2010), fear of social stigma associated with a psychiatric diagnosis led to a raised threshold for treatment initiation.

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In order to approach treatment barriers from a recovery-oriented perspective, it is important to understand patients’ firsthand experiences around the period that clinicians identify as DUP. Despite research identifying early experiential anomalies (Haug et al., 2017; Nelson, Sass, & Škodlar, 2009; Schultze-Lutter et al., 2012), little is known about whether FEP service users experience the DUP as a time during which they needed or wanted additional supports. Indeed, to our knowledge, no studies to date have directly investigated whether subjective approximations of the DUP construct are implicitly given in the lived experiences of service users themselves.

The present project was part of a larger STEP-Early Detection (STEP-ED) study (Srihari et al., 2014), designed to investigate the impact of a public-outreach campaign on DUP at the

community level. The aim of the present project was to investigate service users' subjective experiences and conceptualizations of DUP, to compare service-user understandings to those of clinicians, and to broaden the person-centered research on lived experiences of FEP.

Method

Participants

Participants were 10 service users at an EIS program in Connecticut (four females, six males, $M_{age} = 22.5$ years, age range: 19–26 years). The modest sample size allowed for in-depth qualitative analysis. Half of the sample (five participants) were within two months of intake to the program, and half of the sample (five participants) had received at least one year of EIS. Two participants identified as African American or Black, three identified as mixed race, and four participants identified as white. Recruitment was conducted utilizing convenience sampling; potential participants were identified from within the active roster by intake or treatment team members. Potential participants were invited to participate in a qualitative interview study and, after undergoing a standard informed consent process (including consent for access to clinical records), offered 25 dollars in reimbursement. Research materials and procedures were approved by the Yale University Human Investigations Committee.

Materials

This project utilized basic demographic, psychosocial, and clinical information collected during the standardized STEP-ED research intake process, utilizing the Structured Interview for Psychosis-Risk Syndromes (SIPS version 5.0; McGlashan, Walsh, & Woods, 2001; Woods, Walsh, & McGlashan, under review) for estimating DUI and DUP. Participants subsequently participated in a semi-structured qualitative interview developed for the purposes of the present project. The interview covered the five major topic areas: life before STEP, the onset of experiential changes/difficulties, PtC, desire for support during DUP, and perceptions of FES. Within these topic areas, the interviews followed a person-centered and flexible approach, with optional probe items and follow-up questions as needed. Examples of interview questions include “What was life like for you before you entered STEP?” and “Was there a time before you came to STEP when you wanted more help or support than you were getting?” The interview was developed in consultation with a current STEP patient who provided feedback on the wording of each question and suggested additional items.

Procedures

After informed consent, participants were invited to schedule interviews at their convenience. Interviews were conducted from May to November of 2017, took place in one or multiple sessions; all but one participant opted to complete the interview in one sitting. Interviews were an average of 52 minutes long (range: 31 to 95 minutes). All interviews were audio-recorded and later transcribed verbatim.

Data Analysis

Mixed methods data analysis, employed to compare standardized calculations of DUI/DUP with the participants' subjective perspectives, started with the quantitative SIPS estimates

described above. Next, qualitative analysis utilized a modified version of Giorgi and Wertz's systematic phenomenological procedures (Davidson, 2003; for a review of the philosophical and empirical underpinnings of phenomenology, see Giorgi [2009] and Wertz [2015]). After establishing interrater consistency for individual narratives of each transcript; the narratives were analyzed individually and together to elicit qualitative themes. Themes that were incidental or uncommon among the narratives were discarded. Afterwards, participants' estimates of the time of onset for challenges (symptoms and other difficulties) were extracted using a consensus method among co-investigators (SRK and EH). Service-user estimates were then compared with the SIPS estimates of DUI and DUP.

Findings

In reflecting on their lives prior to mental health treatment, participants described unremarkable daily lives that were disrupted by a period of psychosocial difficulties and life challenges that became overwhelming. For most participants, these difficulties began earlier than SIPS-estimated DUP onset, and there was no consistent relationship between their onset and SIPS DUI estimates. Within this longer trajectory of subjective difficulties, the onset of psychotic experiences was conceptualized as a challenge with unique characteristics. Subjective challenges did not end upon contact with psychiatric services, but rather included these initial contacts. The majority of participants indicated a desire for earlier support of some kind. In the below, these findings are presented in greater detail.

Life Pre-DUP

Daily life as unremarkable—Participants used phrases such as “kind of mundane,” “pretty chill,” and “nothing special” to describe their daily lives and routines prior to the onset of challenges. Participants also reported engaging in social and leisure activities, school, and/or work. These “mundane” daily experiences were sometimes described as positive (e.g., “my life was good”) and sometimes as unsatisfactory (e.g., “I was not super happy with just like going to work and ... having a lot of free time”).

Existential concerns about life as a young adult—Pre-DUP experiences were often characterized by existential concerns about life in general and young adulthood in particular. Participants frequently worried about their educational, vocational, financial, and/or relational futures. For example, Charles¹ lamented: “How am I gonna escape just like continuing to do the same thing with my life?” Jonathan reported “stresses about careers or anti-careers.”

For some, struggles started early—Five of the 10 participants reported struggles that began in adulthood, and half of the participants described substantial challenges during their childhood and/or adolescence. Some participants used clinical terms to describe early difficulties. For example, Rainer stated: “I wanted treatment for anxiety ... [It started] when I was like a teenager.” Some participants reported difficult events such as significant interpersonal losses during their earlier years.

¹All names have been changed to protect participants' privacy.

The Onset of Challenges

Subjective experiences of DUP onset—Comparisons between qualitative findings and quantitative DUP estimates revealed that only one participant described substantial psychosocial challenges beginning at approximately the same time as estimated DUP onset. This participant also described minor challenges (e.g., in work and friendships) leading up to the larger crisis. For nine participants, psychosocial challenges began months or years prior to DUP onset ($M_{\text{difference}} = 42.5$ months prior to DUP onset, range: 2.5 – 210 months). In other words, for all participants, the onset of psychosis was part of a longer trajectory of minor to major psychosocial difficulties that began earlier than and included the DUP time period. This period of time is hereafter referred to as the trajectory of subjective difficulties (TSD).

TSD and DUI onset. Although the TSD typically began before DUP, mixed methods comparisons did not reveal a consistent relationship between TSD and SIPS estimates of DUI onset time. While some participants described a TSD that began before DUI onset, others reported difficulties that began after DUI onset; one participant described subjective changes beginning at approximately the same time as DUI onset. For two participants, DUI estimates were unavailable due to complex PtCs.

Implicit conceptualizations of onset. Participants described the TSD as comprising one or more overwhelming challenge(s) that disrupted previously mundane daily lives. Examples included challenges in work, school, legal situation, lifestyle, and/or relationships. For example, Marc reported “doing far, far too much” to keep up with his busy academic and extracurricular schedule. There were no clear qualitative differences between experiences of TSD in participants within their first two months of EIS treatment and those receiving services for one year or more.

All participants described a TSD characterized by substantial changes, loss, or other difficulties in their interpersonal lives. Examples included death or loss of a family member or friend (e.g., “three people had died in my life in one year”), the end of a romantic relationship (e.g., “I got my heart broken”), a change in family circumstances (e.g., “girlfriend’s about to have her baby ... it didn’t feel real to me”), unhelpful relationships (e.g., “got involved with the wrong people”), increasing distrust in others (e.g., “I thought that my boss was doing something crooked”), increasing isolation and/or loneliness (e.g., “I just don’t have any friends”), an alteration in intersubjective experience (e.g., “it was really creepy the way I was seeing people”), and/or an unusually positive encounter (e.g., “I saw this guy and I felt like he was my soul mate”).

Meanings of DUP within TSD.—For all participants, the onset of psychotic experiences (i.e., the onset of DUP) was meaningfully contextualized by the TSD. In some cases, psychosis was described as one in a series of life challenges; for example, Drew said: “My grandfather passed away ... and then that’s when the thoughts [that people were trying to hurt me] really were brought on.” For others, psychosis onset was perceived as a causal outcome of earlier challenges. For example, reflecting on her murdered friend, Rainer stated:

I knew the guy who killed her, so, that was definitely not fun to go through ... I will sometimes get paranoid that someone is gonna come hurt me, for no reason obviously, and I think that's why.

Like other difficulties within the TSD, psychotic experiences were viewed as a challenge with unique characteristics. Often, they were initially frightening and/or difficult to understand. For example, Drew stated: “[A]t first they were scary, and then ... I learned that they were hallucinations.” In addition, psychotic experiences sometimes carried meanings of potential danger or compromised safety, and they often led to subsequent distressing events such as hospitalization and/or encounters with police. Jonah reported that “[W]hen they [the voices] started telling me to hurt myself, that's when they became a problem,” adding that he subsequently attempted to hurt himself. Although psychotic experiences were distressing, some participants experienced these changes as simultaneously positive (e.g., “I just saw it as kind of a good thing ... like starting to learn like the truth”).

Negative PtC—All participants reported one or more PtC that were experienced as distressing, including encounters with the police, jail, or prison; mobile crisis or ambulance services; emergency departments (ED) or observation units; and hospitalization. Participants depicted negative PtCs as particularly unsettling; for example, Jonathan described the ED as “crazy,” “terrifying,” and “spiritual hell.” Maria stated that the ED staff “just sat me down and kinda broke my heart. Cuz they made me wait for hours.”

Notably, negative PtCs extended the duration of TSD, as distressing contacts with law enforcement, emergency-medical, and/or psychiatric services were experienced as a continuation of difficult life events. As a result, initial contact with treatment often constituted the end of DUP but not TSD. For participants with long or complex PtC characterized by multiple contacts with psychiatric services, initial treatment did not end DUP or TSD.

Experiences during TSD and DUP

For all participants, experiences of TSD (including DUP) involved (1) obstacles to achieving self-sufficiency as well as (2) feeling interpersonally alienated and/or distant from others. Some participants also expressed ongoing spiritual and/or existential concerns.

Obstacles to independence—During TSD and DUP, participants strove towards, but struggled to achieve independence. Financial hardships were particularly common. As Jonathan put it: “Although I was successful ... as far as not milking my parents for ... funds, I wasn't self-sufficient in the truest sense.” Several participants described over-exerting themselves with studies or work. Marc explained: “I definitely was pushing myself to the far limits of sleep, of work ethic ... doing a multitude of things to make my resume look good for college applications.”

Feeling distant and different from others—For all participants, the TSD and DUP were characterized by feelings of distressing interpersonal distance, isolation, distrust, and/or alienation. Whereas some participants reported having limited social support (e.g., “I was the only one that knew I was going through ... I was very alone”), others reported

feeling alienated despite social support that they experienced as insufficient (“My mom, she helped me. She was more my big supporter ... cuz I don’t have nobody”).

Feelings of interpersonal alienation sometimes coincided with feeling *different* from other persons. Paradoxically, thwarted social belonging was both distressing and a source of empathic resonance with others experiencing challenges. Jonathan explained: “[G]oing against the grain, I could meet other people that also felt the same way, but we would lack the resources ... to link up and build a community.”

Spiritual-existential and social justice concerns—For some, TSD was characterized by spiritual-existential and/or social justice concerns. Rainer reported: “I was just thinking about life in general and like trying to answer all of life’s questions.” Marc described a focus on social justice issues after moving to a new neighborhood:

[W]e moved to an inner-city school where it was predominantly Black and I saw people who looked like me, who were genuinely struggling with the same material ... that could’ve been me. So I kind of just had to get my act together and sort of like realized that ... I have a very fortunate life and a lot of people don’t.

When experienced, these spiritual-existential and social justice concerns were meaningfully related to struggles during DUP and TSD. More specifically, perceived difficulties attaining independence and meaningful relationships were viewed through a spiritual-existential and/or social justice lens. For example, Jonathan described his experiences working in a kitchen for underprivileged children:

I can cook food for children who need it ... But I found it to be such a stagnant environment ... It hurt my soul ... I felt a lot of racial tension there, as far as that the people who were running the place were not accurate representations of the people who used it and inhabited it.

The social injustices that Jonathan perceived at his workplace contributed to interpersonal misunderstandings and, eventually, his manager asking him to leave for the day.

Perceptions of Support

Eight of the 10 participants reported that there was a period of time prior to receiving mental health care during which they would have likely benefited from more support than they had. The types of earlier support desired were diverse and included friendships (e.g., “[s]omebody who wants to do the same things I do so I don’t have to be alone”), family relationships (e.g., “living with my mother and father, just talking”), educational/vocational support, financial support, psychotherapy/counseling (“an outside perspective”), psychiatric medications, psychoeducation (e.g., “like something that tells me like ‘okay do this ... and you won’t feel that way’”), social support (e.g., “field trips”), and meta-support for learning about help (e.g., “to learn the general importance of help”; “how to go about seeking it”).

Seven participants estimated the approximate time period during which they would have liked support in general and STEP services (including psychotherapy, medication management, educational/vocational services, and/or social services) in particular. Participants desired support an average of 46.07 months (range: 0 – 84 months) prior to

DUP onset. Six participants voiced a preference for a STEP service prior to the onset of DUP, and one participant indicated that STEP would have been most helpful after her first hospitalization (approximately two weeks after DUP onset). On average, STEP services were desired 24.93 months (range: -0.5 – 84 months) prior to DUP. Some participants voiced a preference for multiple types of earlier support, and some expressed a wish for an earlier start to one element of STEP services (e.g., medication or psychotherapy). The majority of participants emphasized the importance of having someone with whom to share feelings (e.g., a family member, friend, or therapist). Some participants suggested that they would have benefited from earlier support but might not have accepted it due to their symptoms (e.g., paranoia) or other issues (e.g., existential beliefs). Figure 1 depicts the temporal relationship between TSD, DUP, and desired support in the present study.

Two participants stated that they did not believe earlier support would have been beneficial. One of these participants (Jonathan), suggested that intervention during his early psychotic experiences would have been a “*Minority Report*” problem (alluding to a film in which crimes are predicted and prosecuted prior to being committed):

I feel like I’m in a better place now for having gone through what I went through, and sort of to introduce STEP earlier on is kind of a *Minority Report* problem ... [I]t’s sort of like if we could almost anticipate ... poor mental health, then we would stop it before it ever happened ... but I guess for me there wasn’t a better time it would’ve happened...if I didn’t have the spiritual pain that I had, then I wouldn’t feel what I feel now.

Jonathan thus viewed the challenges comprising TSD and DUP, albeit difficult, as part of spiritual growth, and as a result he did not desire earlier intervention.

Life Post-DUP

Although the TSD was often extended by negative PtCs, many participants described positive life changes after entering STEP. Some expressed doubt about the need for treatment (“I didn’t like ... how I felt ... Like something’s wrong with me”). Others initially viewed STEP services as a means of securing discharge from the hospital or avoiding rehospitalization. However, the majority of participants eventually came to value their services. Charles stated: “I was a little apprehensive about the whole idea of like having mental health problems ... [T]he most helpful part of STEP was ... just like talking to people.” Moreover, EIS provided some of the interpersonal, educational/vocational, medical, and even existential supports to which most participants would have preferred earlier access. Marc explained:

And it [STEP] actually ended up being better than an out. It was an opportunity to face my fears, but also just like come to grips with reality, figure out who I really am ... [I]t’s a set of resources that can be utilized to focus your life, find a sense of purpose, autonomy, and some form of mastery.

Another participant, Jonathan, stated:

I consider STEP a blessing, because it ... attempts to address the person as a whole, and not single in on a specific chemical response ... It includes the individual and their own care, and I think that's really cool.

Participants spoke in particularly positive ways about relationships with their STEP clinicians. For example, Drew stated: "I always felt like he [my clinician] was on my side." Maria reported: "I became healed ... I've gotten so much better talking to [my clinician]."

Discussion

Findings revealed that participants experienced and conceptualized DUP within a longer trajectory of subjective difficulties (TSD) that began before standardized DUP estimates. TSD included and extended beyond first healthcare contacts, often experienced as negative PtCs. Within the TSD, participants struggled for self-sufficiency and grappled with feelings of thwarted social belonging. During the DUP, psychotic experiences had the unique characteristics of being confusing, frightening, and/or leading to further difficulties. Most participants believed that earlier support of some kind would have been helpful.

Relationship to Previous Literature on DUP

Subjective versus structured estimates of onset—There was no consistent relationship between DUP estimates and TSD. In addition, TSD began months to years prior to DUP onset (see Corcoran et al., 2003). Therefore, structured DUP and DUP estimates (e.g., McGlashan et al., 2001; Woods et al., under review), while useful clinically, might not fully capture the full temporal trajectory of subjective challenges. Therefore, the TSD construct might be useful in accounting for gaps between clinical parameters of acuity and delayed treatment seeking during DUP. In other words, within a broader trajectory of subjective difficulties, psychosis is not always initially conceptualized as a challenge to address through mental health services.

Diversity of subjective difficulties—Within the TSD, psychotic experiences had the unique characteristics of being frightening and/or perplexing, as well as catalysts for further distressing events such as hospitalization and/or legal difficulties. These findings mirror recent phenomenological studies of both attenuated or prodromal symptoms (Brew, Shannon, Storey, Boyd, & Mulholland, 2017; Hu, 2017) and FEP (Cabassa et al., 2018; Hansen, Stige, Davidson, Moltu, & Veseth, 2018), which have indicated that young adults struggle to understand anomalous experiences that initially seem unfamiliar.

In the present study, participants described overwhelming changes in their interpersonal, educational, vocational, and/or legal situations. These findings reflect extant research suggesting that social marginalization, economic inequalities, and structural deprivation are robust psychosocial risk factors for psychosis (e.g., Bechdolf et al., 2010; Selten, van der Ven, Rutten, & Cantor-Graae, 2013). Further, prolongations of DUP might occur as a result of the person's heightened focus on these other psychosocial challenges, which might be utilized as a heuristic framework within which psychotic experiences are conceptualized (e.g., Bergner et al., 2008; Schalkwyk et al., 2015).

Participants also described perceived obstacles to self-sufficiency and independence. These obstacles overlap with—and thus might be difficult for young persons to readily distinguish from—normative challenges of emerging adulthood (e.g., Lamborn & Groh, 2009). Indeed, previous research has indicated that normalization of severe distress is a barrier to treatment in young adults with psychosis and other high-risk symptoms (e.g., Czyn et al., 2013; Jansen et al., 2015a, 2015b). In some cases, the belief that psychotic experiences are themselves a meaningful developmental task to experience and overcome might—in what one participant called the *Minority Report* problem—lead to avoidance of healthcare.

Spiritual-existential and social justice concerns.

Several participants focused on spiritual-existential or social justice concerns (e.g., self-actualization or combating urban poverty). Previous research has suggested that spiritual and existential interpretations of mental distress are not necessarily experienced as conflicting with, but rather often held simultaneously with biomedical explanations (Jones, Kelly, & Shattell, 2016). Concerns about social justice might reflect social-epidemiological evidence indicating that social marginalization (Selten et al., 2013), neighborhood income inequality (Kirkbride, Jones, Ullrick, & Coid, 2014), and other structural disparities are psychosocial risk factors for psychosis that interact with biological diatheses. In other words, personal experience of social inequalities could heighten attention to others' hardships. While it is unclear whether spiritual-existential and social justice concerns impact the length of DUP or TSD, their prominence suggests that early intervention efforts incorporating these themes, such as structural competency interventions that address social and racial disparities (e.g., Metzl & Hansen, 2014), might be appealing to young adults who experience them.

Negative PtC—Participants in the present study reported negative PtC, or treatment contacts that were experienced as distressing and/or coercive. The unsettling nature of these contacts lengthened the TSD; participants with particularly long and complex PtCs described multiple contacts that were perceived as unhelpful. This reflects previous research indicating that DUP can be prolonged by avoidance of potentially distressing treatment encounters, especially those perceived as leading to social stigma (Franz et al., 2010). A subsequent manuscript (Hyun, in development) will detail the relationship between participants' negative PtC and experiences of DUP.

Early detection and support—The majority of participants desired earlier support of some kind during the TSD. Desired types of support were diverse and included social (friendships and family), educational/vocational, psychotherapy/counseling, psychoeducation, medication, and meta-support. Notably, STEP services were desired (on average) more than two years prior to DUP onset. This finding indicates resonance between service users' and professionals' beliefs about psychosocial intervention during the prodromal phase (e.g., Nelson et al., 2009).

Findings indicated three potential barriers to early supports: first, there was substantial diversity in the types of support(s) desired, with some participants desiring certain types but not others (e.g., psychotherapy without medications or vice versa). Second, participants often indicated that despite potential benefits, they did not know how to locate early support

or whether they might have accepted it. Third, earlier support was not ubiquitously desired, as a minority of participants denied its potential helpfulness. These potential barriers suggest that although early FEP supports might be appreciated, their provision would entail diverse person-centered targeting of both psychosocial and clinical needs, as well as the shared-decision making practices reflected in the coordinated specialty care model (e.g., Montori, Brito, & Murad, 2013).

Limitations

Limitations to the present study included the sample size, which precluded comparisons across demographic groups; use of convenience sampling and recruitment from a single EIS program, which prevented generalization of the findings to other EIS models and broader early psychosis populations; lack of a comparison sample; and limited access to family members, which prevented comparisons between service user, family, and clinical conceptualizations of DUP. Importantly, the present data relied on retrospective reports of DUP experiences in EIS service users. Retrospective interviews can introduce potential reporting biases such as recall bias (e.g., McMurrich, Johnson, & Peckham, 2012), and in this project might have influenced subjective comparisons between pre-, peri-, and post-DUP experiences, as well as views of whether earlier EIS services would have been helpful.

Future Research Directions

Future research should compare the onset of DUI with TSD in a larger sample in order to further investigate the relationship between standardized assessments of prodromal experiences and subjective challenges. In addition, future studies might evaluate experiences of TSD and DUP in young adults experiencing FEP, same-aged peers with other challenges, and nonclinical populations. Subtle differences between experiential strivings for self-sufficiency in young adults with and without FEP experiences could lead to enhanced EIS. In addition, it is important to understand the experiential relationship between the TSD and conversion to psychosis in high-risk populations. The present findings might also be a starting point for the development of person-centered measures for assessing DUI, DUP, and TSD; inclusion of TSD as a supplementary construct alongside standard DUI and DUP measures might allow for assessments of relationships between subjective experiences and structured estimates of symptom onset. Future research is also necessary to understand the diversity of early supports and corresponding person-centered interventions that might appeal to transition-age youth and young adults experiencing early psychosis.

Conclusions

Young adults experiencing FEP conceptualize the period of time identified by health professionals as DUP within a longer trajectory of other subjective difficulties. Although psychosis is experienced as a unique challenge—frightening, confusing, and leading to further hardships—its subjective embedding within the TSD suggests that delayed treatment might result from lack of attention to specialized resources. Future early detection and intervention efforts might be enhanced by a person-centered focus on the distinct temporal frame and subjective themes within the TSD. More specifically, future efforts might focus on strivings towards self-sufficiency, social belonging, and, for some transition-age youth, spiritual-existential and social justice concerns.

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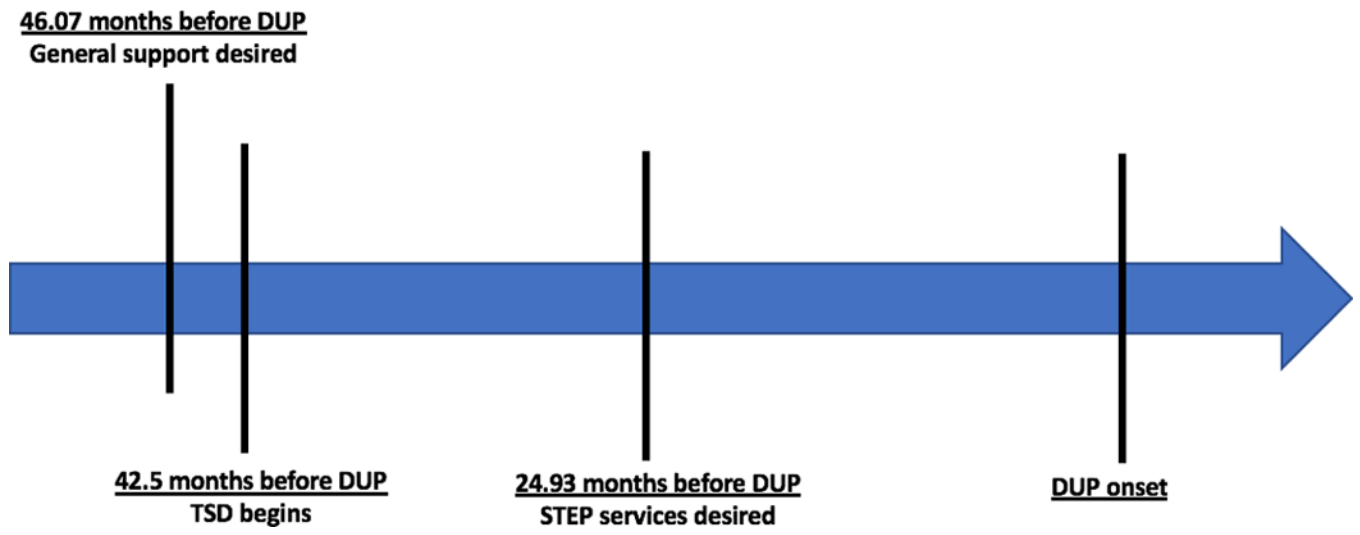


Figure 1.
Relationship between TSD, DUP, and desired support.

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