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First help-seeking attempt before and after psychosis onset: measures of delay and aversive pathways to care

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Abstract

Purpose—Delay in receiving effective treatment for psychosis adversely impacts outcomes. We investigated the timing of the first help-seeking attempt in individuals with recent onset non-affective psychosis by comparing those who sought help during the prodrome to those who sought help after psychosis onset across sociodemographic and clinical characteristics, overall functioning, and occurrence of aversive events during their pathways to care.

Methods—Patients were admitted from February 1st, 2014 to January 31st, 2019 to the Program for Specialized Treatment Early in Psychosis (STEP) in New Haven, CT. Psychosis onset date was ascertained using the Structured Interview for Psychosis-risk Syndromes. Key dates before and after psychosis onset, along with initiators and aversive events were collected via semi-structured interview.

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Conflicts of interest/Competing interests The authors declare that they have no conflict of interest.

Ethics approval The study have been approved by the Yale University Institutional Review Board and have therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments.

Consent to participate Informed consent was obtained from all participants per procedures of the study protocol approved by the Yale University Institutional Review Board [page 6 of the manuscript].

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Results—Within 168 individuals, 82% had their first help-seeking episode after psychosis onset, and did not differ in terms of sociodemographic characteristics from prodrome help-seekers. When the first help-seeking episode started before (i.e. during prodrome) vs after psychosis onset, it was mostly initiated by patients vs family members (Cramer's V =0.23, p=.031) and led to a faster prescription of an antipsychotic once full-blown psychosis emerged (time to antipsychotic since psychosis onset= 21 vs 56 days, p=.03). No difference in aversive events before STEP enrollment was detected across groups.

Conclusion—Help-seeking during the prodrome is associated with faster initiation of antipsychotic treatment and is more likely to be self-initiated, compared to help-seeking after psychosis onset. Early detection efforts that target prodromal samples may improve the length and experience of pathways to care.

Keywords

First Episode Psychosis; Pathways to Care; Help-Seeking Behaviour; Duration of Untreated Psychosis; Early Intervention; Early Detection

Introduction

There is a need to improve the speed and tolerability of pathways to care for individuals with first episode psychosis (FEP). Help-seeking attempts during psychosis, when contact with reality and insight is poor [1], are unfortunately often triggered by aggressive or dangerous behavior towards oneself or others, leading to aversive events along the pathways to care, often involving police, emergency rooms, and involuntary psychiatric hospitalization [2]. Such aversive experiences might reduce trust and adherence to care in subjects, ultimately hampering recovery [3–5]. Delay to effective treatment is associated with poorer short and long-term outcomes [6–9]. Seminal early detection (ED) efforts, such as the Scandinavian TIPS study, demonstrated that halving the duration of untreated psychosis (DUP) produced benefits evident ten years later [10,11].

In up to 70% of cases, psychosis is preceded by a variably defined prodromal period [12] that is itself characterized by subthreshold symptoms of the disorder and reductions in social, academic, or general functioning. However, recent data from South London (UK) FEP services show that only a minority of individuals with FEP (4.1% of 338) had sought help for pre-onset subthreshold symptoms of psychosis at the prodromal service[13], confirming a US retrospective study in which only 14.5% of a FEP sample sought professional help during the prodrome [14]. Such findings have led to calls to extend early detection efforts, that are typically focused on those who have already manifested frank psychosis, to prodromal samples [15]. Referrals from high-risk for psychosis versus generic mental health care service have been associated with reduced frequency and duration of hospitalization [16] and offer the potential of delaying or preventing the onset of psychosis[15] [17]. While definitive evidence on prodrome focused detection is unavailable, these data highlight the importance of understanding pathways to care during this phase of schizophrenia[15,18].

The first help-seeking episode can play a pivotal role in a young patient's experience of the healthcare system. This often includes actions undertaken by multiple agents: patients, caregivers, and a network of community stakeholders (e.g. police, teachers), who shape access to and engagement with care[19]. The study of the first help-seeking episode can reveal how events unfold in the real world in order to foster optimal early detection efforts. In order to tailor early interventions and ultimately prevent treatment delays, it is important to understand how individual characteristics and timing of the first instance during which patients or caregivers seek help for psychosis influence participants' interactions with the healthcare system.

There is limited knowledge of the first help seeking episode in early schizophrenia. A study conducted in Ireland found that, within 142 subjects diagnosed with FEP, only 40% sought help for themselves after the psychotic illness had started and even fewer (25%) sought help during the prodrome [20]. The authors also reported distinct factors that affected delay across illness phases. During the prodromal phase, but not after psychosis onset, male gender, poorer premorbid adjustment, and negative symptoms at admission were associated with delays. During the psychotic phase, family involvement in help-seeking attempts reduced delays. Thus, demographic, socio-economic, and clinical features of help-seekers need to be better characterized to prevent delays to care and improve the choice of provider of such care.

In this study, we analyzed the first help-seeking attempts of individuals admitted to a specialty team-based psychosis service (FES) to investigate whether those seeking help before psychosis onset (as ascertained by a structured interview) differed from those who sought help after psychosis onset in terms of sociodemographic and clinical characteristics, overall functioning, and occurrence of aversive events during their pathways to specialized care.

Methods

Sampling

Subjects for this analysis were drawn from consecutive admissions to a community health center-based FES (Specialized Treatment Early in Psychosis, STEP) over five years (February 1st, 2014, to January 31st, 2019). STEP's broad eligibility criteria includes between the ages 16–35 who were within the first three years of psychosis onset, and also met Structured Clinical Interview for DSM-IV TR diagnosis for any non-organic schizophrenia-spectrum or schizoaffective psychosis, including schizophreniform disorders, brief psychotic episode, and psychosis NOS. Services were also restricted to residents in a ten town catchment contiguous with the clinic in New Haven, Connecticut. The clinic excluded referrals with an established diagnosis of affective psychosis (Bipolar Disorder and Major Depressive Disorder with psychotic features), and psychosis secondary to substance use or a medical illness. For most of this period, STEP hosted an early detection campaign that sought to recruit a representative sample across the catchment area [21]. Informed consent was obtained from all participants per procedures of the study protocol approved by the Yale University Institutional Review Board.

Definition of prodrome and psychosis onset

The Structured Interview for Psychosis-Risk Syndromes (SIPS), Version 5.3, was administered at enrollment to identify onset of psychosis and clinical high risk syndromes (CHR)[22].

SIPS categorizes risk of progression to full blown psychosis with three non-mutually exclusive clinical high risk syndromes: the Brief Intermittent Psychotic Syndrome (BIPS), Genetic Risk and Deterioration (GRD) Syndrome, and Attenuated Positive Symptom Syndrome (APS) [23]. BIPS is rare and includes very short episodes qualitatively very similar to full-blown psychosis, even though of shorter duration and less frequent, thus making ascertainment prohibitively difficult after psychosis onset. The GRD syndrome does not capture progression from subthreshold positive symptoms to full blown psychotic severity [21,24]. We thus included only APS, which is the most common CHR syndrome[25], and is defined as the presence of recent attenuated positive symptoms with a specific severity and frequency (i.e. hallucinations must be at least captivating or puzzling, and have occurred at least once per week in the previous month) [22]. Based on available literature [12,26], we expected that APS would not be identifiable for a subset of patients. For this analysis we have therefore used only cases where an identifiable APS date was present (with a prodrome start date corresponding to the APS syndrome onset date). Despite a lack of consensus on what constitutes the prodrome and how to measure it, the APS syndrome was selected to date prodrome onset because it was most reliably identifiable in retrospective interviews of our sample and also closest to the DSM-5 defined attenuated psychosis syndrome [27,25].

Psychosis onset was defined as meeting the Presence of Psychotic Syndrome (POPS) criteria of the SIPS. The rated symptoms must have occurred over a period of one month for at least one hour per day at a minimum average frequency of four days per week, or the symptom must have been seriously disorganizing or dangerous[24] [22] (the Appendix includes a detailed description of the criteria for high-risk syndromes and psychosis).

Overall impairment in functioning due to mental health factors was assessed with the Global Assessment of Functioning (GAF) scale at admission [28]. The GAF score reflects the overall impairment in the past 30 days, with a single score ranging from 1 to 100, where a higher score represents better functioning.

Measures of Delay

For this sample of FEP individuals, we were able to retrospectively build a detailed narrative of the continuum between the prodromal period and onset of psychosis. Per inclusion criteria, the progression of symptoms led to psychosis in the whole sample, therefore we considered duration of untreated illness (DUI) as the interval from APS syndrome onset date to the first prescription of antipsychotic medication for psychosis [see Fig. 1] [29]. The APS interval was defined as the time from APS onset to psychosis onset (per POPS criteria).

The interval between the onset of psychosis to admission to STEP was defined as DUP-total. It is further divided into the “demand” and “supply” sides of delay to specialized care, DUP-demand, and DUP-supply, respectively [21]. DUP-demand, defined as the time interval from

psychosis onset to the first prescription of an antipsychotic for psychosis, includes the delays in illness identification, and help-seeking by participants and caregivers. The first prescription of antipsychotic for psychosis is a proxy for accurate identification and initiation of treatment for psychosis by a healthcare provider (and excludes off label prescriptions of antipsychotics, e.g. for sleep disturbances). DUP-supply, the time interval from the first prescription of antipsychotic to admission to STEP, cumulates delays attributable to actors in the healthcare system in enrollment into best practice care (i.e. local FES or STEP) [see Fig. 1] [21]. For those instances when an individual was antipsychotic-naïve at STEP admission, DUP-supply was zero, and DUP-total equaled DUP-demand.

Pathways to care (PTC)

The STEP-ED PTC Scale, adapted from the Pathways to Care Interview [30,31], assessed help-seeking by guiding interviews of patients and systematic collection of collateral from caregivers and clinical records. This resulted in detailed information about each help-seeking attempt, including symptomatic or behavioral precipitants, to whom participants turned for help, the outcome of each help-seeking attempt, and perceived barriers to care.

This study focused on the first help-seeking episode (HSE). Details about critical dates when someone (either patient, family, or others) first noticed a change in behavior related to psychosis were also recorded and analyzed. A help-seeking episode begins when someone (patient, family, others) seeks help *for symptoms that are attributable to psychosis (change in thinking, feeling, or behavior)* and ends when either the patient falls out of mental health treatment or enrolls in FES.

The onset of psychosis was defined as the date that POPS criteria were met. All patients were divided into two groups based on whether their first HSE was before (Prodromal-HS) or after (Psychosis-HS) psychosis onset.

As represented in Fig. 1, important measures of delay were derived from the scale. Specifically, within DUP-demand are more granular measures of delays in help-seeking: the time interval between the awareness of psychotic symptoms and the initiation of the first HSE by the family (DHSf) or the patient (DHSp). Subsequent to this is the delay in help finding (DHF), or the delay to receipt of the first antipsychotic. In the case of Prodromal-HS, DHF could include a prodromal period when the prescription of an antipsychotic is not indicated.

From the PTC interview, we also selected indicators of aversive pathways to care from the first help-seeking attempt to STEP admission. These indicators included encounters with the police (as initiator of a help-seeking attempt and/or as recipient of a request for intervention by patients or caregivers), and involuntary hospital admissions to inpatient psychiatric units.

We used an adapted version of the Service Utilization and Resources Form (SURF) to retrieve information about the number and duration of hospitalizations in inpatient psychiatric units in the six months preceding admission to STEP [32,33].

Statistical analysis

In this exploratory study, demographics, including age at first HSE, age at POPS, age at enrollment, race, and gender; clinical characteristics, including diagnosis, GAF at enrollment, and sources of delay; socioeconomic variables, including employment status, and household income (categorical variable dichotomized at $40,000) were compared between Prodromal-HS and Psychosis-HS participants. Three participants who did not have complete PTC and SIPS were excluded.

In order to investigate if the start of the first help-seeking episode (HSE) correlated with prolonged delays to entering care, the groups (Prodromal-HS vs Psychosis-HS) were compared across various measures of delay (as detailed above and in Fig. 1).

Finally, Prodromal-HS and Psychosis-HS were compared across measures of aversive events during pathways to care: the total number of contacts with the police, the total number and duration of hospital admissions to psychiatric inpatient units (voluntary and involuntary). Based on the contact made by the initiator during the first HSE, participants were classified into one of the three following categories: family and community resources (family, friends, school, social welfare agency, consumer's and youth organization), health service providers-potential prescribers (emergency department, hospital, private practice, mental health clinic, adult and child primary care provider), or police.

Demographic and clinical characteristics were compared across three groups using ANOVA or Kruskal-Wallis test depending on normality for continuous variables, and Chi-square test for categorical variables. SAS 9.4 (Cary, NC) was used for all statistical analyses. The statistical significance level was set at $p< 0.05$, two-sided.

Results

Sample characteristics

The sample comprised of 168 FEP participants from 202 eligible referrals. Those who were eligible but refused to be admitted to the program (n=34) did not differ from the final sample by age or gender distribution. The final sample was predominantly male (118, 70%), racially diverse, and young (mean age at admission was 22.4±3.8) (Table 1). The majority were diagnosed with schizophrenia and significantly impaired in general functioning at admission to STEP (median GAF score was 31.3±10.7), and 88.1% had an identifiable APS onset date. Eighty-two percent of the individuals in this sample (n=138) experienced their first help-seeking episode after psychosis onset, i.e. were 'Psychosis help-seekers' (Psychosis-HS). Those who sought help during the prodromal period of their illness, i.e. the Prodromal-HS group (n= 30), were on average two years younger when they sought help (20.3±3.3 vs 22.1±3.0 for Psychosis-HS, $p<.02$). While off label antipsychotic prescription during the prodromal phase was infrequent overall (n=5, 17%), the two groups did not differ in this respect. Within the prodromal-HS (n=3), aripiprazole was prescribed for depressive symptoms (n=2), or for subthreshold psychosis symptoms (n=1). Within Psychosis-HS (n=2) one patient was prescribed quetiapine for anger management, and one aripiprazole for depression.

Delays to Care

The Prodromal-HS and Psychosis-HS groups showed similar durations of APS and untreated illness (DUI) (Table 2).

Patients who had first sought help during the prodrome (i.e. Prodromal-HS) took expectedly longer to get prescribed an antipsychotic for psychosis after initiating help seeking (median 245 days [range: 5–1400] vs. 1 day [0 – 999], $p<0.001$ for Psychosis-HS) (Table 2). However, it took significantly less time for Prodromal-HS patients to receive an antipsychotic after psychosis onset (median DUP-demand 21 days [range 0 – 445] vs. 56 days [0 – 1153, ($p=.03$) for Psychosis-HS]. This difference in DUP-demand, however, was not present when we excluded nine Prodromal-HS who were already in psychiatric care prior to transition to full blown psychosis, and thus did not need to subsequently initiate help seeking ($p=0.21$).

Prodromal-HS subjects did not show a significant reduction in delays to enrollment at STEP once they crossed the threshold for psychosis: median DUP-total 109 (2–1008) days vs 184 (4–1189) days; $p=.30$ (Table 2).

Pathways to care

There was a significant association between the timing of the first HSE and type of help-seeking initiator. The first HSE was more likely to be initiated by the patient during APS, but by the family after psychosis onset (chi-square =6.932, $p=.032$, with a medium Cramer's V effect size =0.23, $p=.031$) (see Fig. 2).

Table 2 shows patient- and family-side delays (time interval between when the patient or family respectively noticed a change, to the initiation of HSE, see Fig. 1), which were not significantly different between the two groups. Of note, during the prodromal phase, 70% of patients, compared to only 33% of family members acknowledged a change in patient behavior/thinking before the first HSE. After psychosis onset, 91% of patients and 68% of family members noticed similar changes. Regardless of who first noticed a change (either family, patient, or others), the delay for this person to set in motion the first HSE from the moment a change was perceived was not different between Prodromal-HS and Psychosis-HS groups ($p=0.06$).

Table 3 reports the frequency of aversive pathways to care, which did not significantly differ across the two groups. For the whole sample, 23% had at least one encounter with the police and 32% had at least one involuntary admission to the inpatient psychiatric unit before their admission to STEP.

Age, gender, and symptom threshold severity (prodrome vs psychosis) did not significantly impact on the type of first responder or contact at the terminus of the first help seeking episode (either family/community resources, health care providers, or police) (Table 4). The choice made by the HSE initiator for the first contact did not significantly influence the delay to receive the first antipsychotic or enrollment to STEP (DUP-demand n.s. $p=.93$, DUP-total n.s. $p=.14$) (Table 4).

The vast majority of encounters with the police during the first HSE occurred after psychosis onset (17/18, 94%), and involved mainly male patients (15 men vs 3 women).

For the Prodromal-HS group, in most cases the initiator connected with a health care provider (20/30, 66%). In contrast, for Psychosis-HS, the initiator was less likely to reach health care providers first (73/138, 52%), but instead another family or community member was involved in 34% of cases (48/138).

Discussion

This is the first U.S. study to quantitatively interrogate the comparative impact of help-seeking in the prodromal versus post-psychotic phases of recent onset schizophrenia. Several findings illuminate the similarities and differences in the speed and quality of the ensuing pathways to specialty care. The vast majority of enrollees to our population-based FES reported their first help-seeking episode only after psychosis onset (82%). The two groups, classified by whether they first sought help during the prodrome (Prodromal-HS) vs after psychosis onset (Psychosis-HS), did not differ in terms of demographic (gender, race, age at psychosis onset or admission to care), socioeconomic (accommodation, household income) or functional (GAF) variables at enrollment. When help-seeking was initiated during the prodrome, patients were more likely than family members to be the initiators, while the reverse was true after psychosis onset. Help-seeking during the prodrome was associated with shorter delays to first antipsychotic treatment after psychosis onset (DUP-demand median of 21 vs. 56 days), reflecting a clear benefit of being in care during conversion to psychosis [34]. This did not however, result in faster referral to the local FES, or shorter Dup-total. Other reports have suggested that being in treatment during the prodromal phase might actually prolong DUP [35], and this presents a target for future efforts to improve pathways to specialty care. Five subjects were prescribed an antipsychotic during the prodromal phase of the illness [36]: four out of five prescriptions targeted depression and anger and only one addressed emerging subthreshold psychosis symptoms. This is consistent with our prior demonstration of the predictive validity of the SIPS threshold used here to distinguish the prodrome from psychosis [24].

The frequency of aversive events was surprisingly not significantly different between the two groups. While as many as one in five patients had at least one interaction with the police before enrollment in our FES, reassuringly this rarely resulted in incarceration and might reflect the unusually active role of jail diversion and crisis intervention teams in our catchment [37]. The degree of police interception and inappropriate diversion to the criminal justice system of illness related disruptive behavior is likely higher in other regions [38–40]. Thus our sample may have underestimated the putative benefits of self-initiated help-seeking prior to psychosis onset. Similarly, we did not find a difference in the frequency of involuntary hospitalization between the two groups.

The strengths of this approach included the use of the SIPS instrument to both explicitly identify and date the onset of the prodromal phase and the transition to full-blown psychosis. When integrated with the detailed pathways to care interview, this allowed a granular measurement of the pathways that patients and their families undertook as they accessed

care, both in terms of time (delay) and quality (aversive interactions). Both of these elements may have prognostic value in terms of predicting responsiveness to care, but also are measures of the health of a local referral network. This approach thus provides actionable information for early detection efforts. For example, our data showed that the vast majority of patients did acknowledge a change in their behavior or thinking, yet this awareness was a more reliable trigger for help-seeking during the prodromal phase than after full-blown psychosis onset. This may be related to the common loss of insight after psychosis onset, with the family needing to assume the role of initiating efforts to access healthcare. However, family members may wait too long to seek help, when severe symptoms increase the likelihood of aversive events (involuntary hospitalization or entanglement with the criminal justice system) that can reduce long-term engagement with care [41]. Our results support proposals for early detection efforts targeting prodromal samples to reduce DUP, as those in care during the prodrome benefited from a shorter Demand side DUP[42]. However specific efforts may be required to hasten subsequent referral to specialty FES. We were unable to show a reduction in measures of aversiveness (involuntary admission, police involvement) of pathways when help seeking occurred during the prodrome, but, the greater agency of prodromal help seekers in our sample may have independent value[43], and better leverage the impact of specialty care [44]. These findings were derived from a defined catchment in the Greater New Haven region that is highly representative of U.S. demography [45], and a clinical sample with illness severity and socioeconomic characteristics that are likely representative of the kinds of early psychosis patients who present for care in community settings.

Notably, we were unable to either confirm or rule out prodromal symptoms in only 4.2% of the sample. This is considerably lower than prior reports of 30% [12] without confirmed prodromes, but were limited by a lack of psychometric assessment of early symptom onset and severity. The SIPS, which was designed to differentiate prodromal from threshold psychosis, demonstrates utility here in dating both these illness phases and their interaction with pathways to care [46].

The methodology described here could guide useful analyses in other systems of care and reveal actionable targets to improve the speed and quality of access to best practice care. The rapid dissemination of Coordinated Specialty Care (CSC) services across the U.S. and increasing availability of similar clinics for recent onset psychotic disorders around the world makes a focus on access to such services a logical next step in service delivery. The reported analysis did not specifically address the effect of an ongoing early detection campaign [21]. Future time trend analyses might reveal which specific aspects of the pathway were impacted by this ongoing campaign.

Conclusions

Timing of first help-seeking in early psychosis can be crucial in shaping both the duration and experience of pathways to care. Help-seeking during the prodromal state was associated with shorter delays to appropriate antipsychotic treatment, and was more likely to be self-driven. Early detection efforts targeting prodromal samples have the potential to yield

greater reductions in DUP, while also revealing opportunities to engage the agency of emerging adults in specialty treatment.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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The preliminary results of this work have been accepted as poster presentation at SIRS 2020, Florence. Abstract is available as **Maria Ferrara***, Sinan Guloksuz, Walter Mathis, Andrea Raballo, Fangyong Li, I-Hsin Lin, Sumaiyah Syed, Keith Gallagher, Scott Woods, Cenk Tek, Vinod Srihari. T242. The timing of first help-seeking attempt in first episode psychosis can lead to aversive pathways to care. Results from the STEP-ED study. *Schizophrenia Bulletin*, Volume 46, Issue Supplement_1, April 2020, Page NP, https://doi.org/10.1093/schbul/sbaa028

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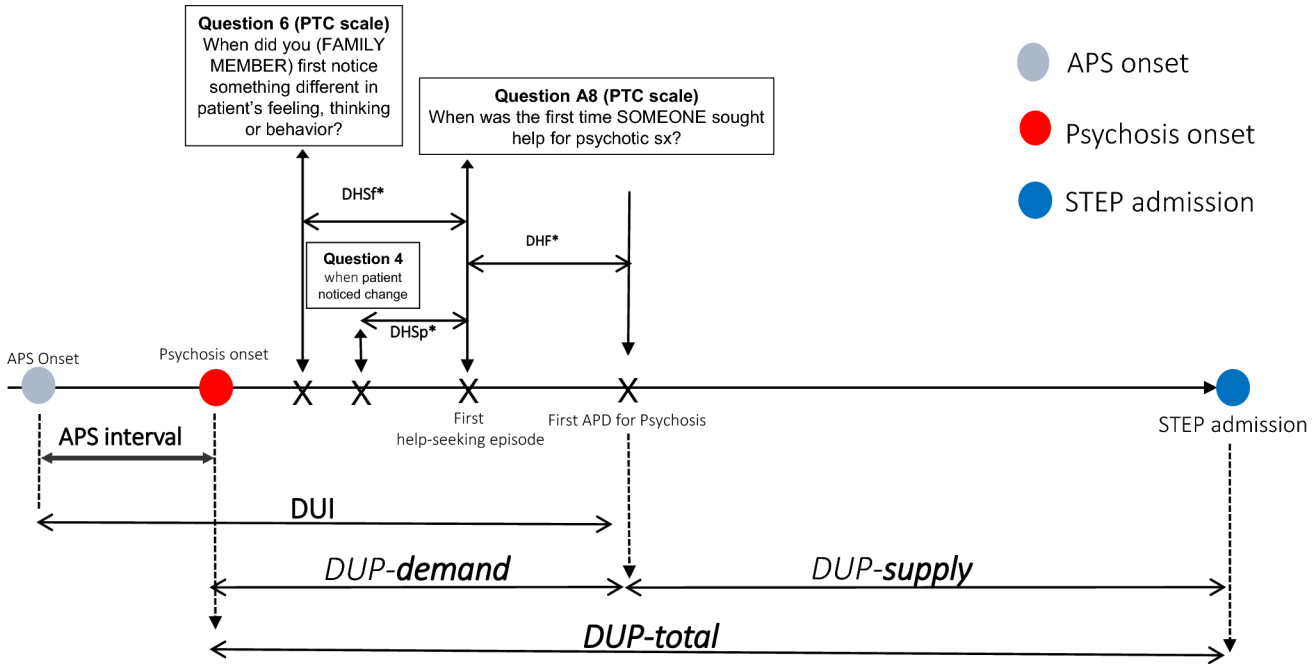

Fig. 1.

Pathways to care in first episode psychosis. Definitions of measures of delay. **PTC** Pathway to care. **APS** = Attenuated Positive Symptoms Syndrome **DUI** = Duration of untreated illness. **APD** = antipsychotic drug. **STEP** = Program for Specialized Treatment Early in Psychosis. **DHSp*** = Delay initiating Help-Seeking (patient); **DHSf*** = Delay initiating Help-Seeking (Family). **DHF** = Delay in Help-finding. *can be prior to, or after, Psychosis onset defined as the date on which Presence of Psychotic Syndrome (POPS) criteria within the Structured Interview for Psychosis-Risk Syndromes (SIPS) were first met.

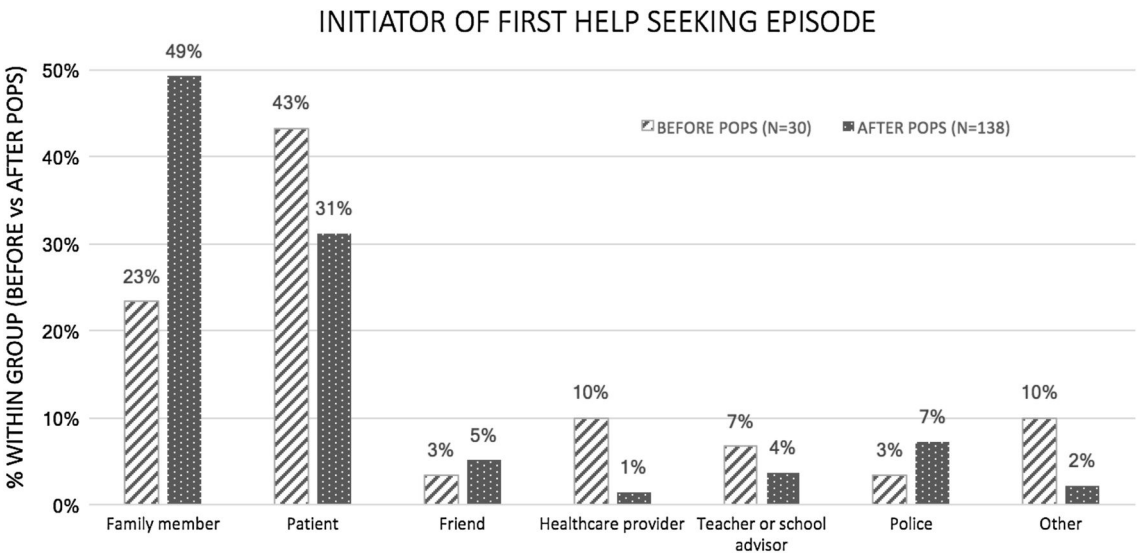

Fig. 2.

Initiators of the first help-seeking attempt during prodromal (pre-POPS) vs psychotic (post-POPS) phase.

Table 1

Frequency characteristics of the study population **(N=168)**

Variable	Total sample	First help-seeking episode before POPS *N*= 30	First help-seeking episode after POPS *N*=138	Difference *p*-value
Gender, M, n (%)	118 (70%)	20 (66.7%)	98 (71.0%)	0.64
Race, n (%)				0.16
Black (e.g. African, African Caribbean)	75 (44.6%)	11 (36.7%)	64 (46.4%)	
White (European)	57 (33.9%)	14 (46.7%)	43 (31.2%)	
Interracial	26 (15.5%)	2 (6.7%)	24 (17.4%)	
Other	10 (6.0%)	3 (10.0%)	7 (5.1%)	
Age at different time points				
Age at admission,				
mean (SD)	22.4 (3.8)	21.7 (3.2)	22.6 (3.9)	0.22
median [range]	21.5 (16.0 – 34.5)	21.3 (16.0 – 27.3)	22.0 (16.0 – 34.5)	0.30
Age at first Help seeking attempt				
mean (SD)	21.8 (3.8)	20.3 (3.3)	22.1 (3.9)	0.02
median [range]	21.0 (14.8 – 33.4)	19.3 (15.1 – 26.6)	21.3 (14.8 – 33.4)	0.02
Age at Psychosis onset (POPS)				
mean (SD)	21.6 (3.8)	21.0 (3.3)	21.8 (3.9)	0.41
median [range]	21.0 (13.7 – 33.1)	20.4 (15.2 – 26.7)	21.0 (13.7 – 33.1)	
Prodromal phase				
CHR with identifiable APS onset date	148 (88.1%)	30 (100.0%)	118 (85.5%)	
CHR without identifiable APS onset date	4 (2.4%)	0 (0.0%)	4 (2.9%)	
No presence of CHR/APS, very acute onset of psychosis	7 (4.2%)	0 (0.0%)	7 (5.1%)	
Undetermined presence/absence of prodrome (unable to determine)	9 (5.4%)	0 (0.0%)	9 (6.5%)	
Living situation in the 6 months before admission				
With family	147 (88.6%)	27 (90.0%)	120 (88.2%)	0.78
With spouse/partner	9 (5.4%)	3 (10.0%)	6 (4.4%)	0.22
In a shelter	7 (4.2%)	5 (3.7%)	2 (6.7%)	0.46
On the street	5 (3.0%)	1 (3.3%)	4 (2.9%)	1.00
Incarcerated	2 (1.2%)	0 (0.0%)	2 (1.5%)	1.00
Household income				
Less than $40,000	66 (39.3%)	9 (30.0%)	57 (41.3%)	0.23
$40,000 and above	83 (49.4%)	19 (63.3%)	64 (46.4%)	
Don’t know or refused	19 (11.3%)	2 (17.8%)	17 (12.3%)	
GAF at admission				
mean (SD)	31.3 (10.7)	29.1 (11.9)	31.8 (10.4)	0.22
median [range]	31.0 [8.0 – 79.0]	21.0 [20.0 – 63.0]	31.5 [8.0 – 79.0]	0.09

CHR: clinical high risk syndrome, as assessed by the Structured Interview of Psychosis-risk Syndromes (SIPS). APS syndrome: attenuated positive symptoms syndrome, as assessed by the Structured Interview of Psychosis-risk Syndromes (SIPS). GAF: Global Assessment of Functioning.

Table 2

Comparison of delays along the pathway to care: first help-seeking attempt before (Prodromal-HS) vs after psychosis onset (Psychosis-HS)

Delays to care, intervals	Prodromal-HS *N*=30	Psychosis-HS N=138	*p*-value
APS interval, days			
mean (SD)	581.5(618.7)	530.7 (779.2)	
median [range min max]	363.5 [31.0 – 2571]	197.0 [1.0 – 4567]	0.18
DUI, days			
mean (SD)	653.7 (622.4)	669.2 (808.5)	
median [range]	441.5 [49.0, 2575]	389.0 [2.0, 5104]	0.61
DUP-demand, days			
mean (SD)	72.2(110.6)	166.5(243.1)	
median [range]	21.0 [0.0 – 445.0]	56.0 [0.0 – 1153]	0.03
DUP-total, days			
mean (SD)	242.0 (266.4)	298.3(308.2)	
median [range]	109.0 [2.0 – 1008]	184.0 [4.0 – 1189]	0.29
DUP-supply, days			
mean (SD)	169.8 (255.5)	131.8 (231.0)	
median [range]	25.50 [1.0 – 941.0]	21.0 [0.0 – 1106]	0.65
Delay in help finding (DHF), days,			
mean (SD),	337.8 (348.2)	43.0 (138.7)	<.0001
median [range]	245.0 [5.0 – 1400]	1.00 [0 – 999.0]	
DHSp Patient side delay, days,			0.09
mean (SD)	162.7 (324.1)	291.0 (600.0)	
median [range]	14 [0 – 1093]	75 [0 – 3928]	
N available(%)	N=21(70%)	N=126(91%)	
DHSf Family side delay, days			0.36
mean (SD)	82.9 (120.8)	199.6 (422.9)	
median [range]	14.5 [0 – 266]	31.0 [0 – 2949]	
N available(%)	N=10(33%)	N=95(68%)	

APS = Attenuated Positive Symptoms Syndrome. DUI: duration of untreated illness. DUPd: time interval between psychosis onset (POPS date) to first prescription of antipsychotic. DUPt: time interval between psychosis onset (POPS date) to admission to STEP program. DUPs: time between the first APD prescription to STEP admission. STEP = Program for Specialized Treatment Early in Psychosis. DHF: Delay from the first time someone sought help and first antipsychotic prescription. DHSp = Delay initiating Help-Seeking (patient). DHSf= Delay initiating Help-Seeking (Family). For further details see Figure 1.

Table 3

Comparison of aversive pathways to care: first help-seeking attempt before (Prodromal-HS) vs after psychosis onset (Psychosis-HS)

			Prodromal-HS N=30	Psychosis-HS N=138
Contact with the police	Total number of **contacts** with the police (sum of police as initiator, and police as responder in all help seeking episode in PTC interview)	Subjects who had at least one contact	7 (23%)	32 (23%)
		Total number of contacts	8	42
		Median [range]	1 (1–2)	1 (1–4)
Psychiatric Hospital admissions	Hospital admissions across **all** help seeking episodes	Subjects who had at least one hospital admission	25 (83%)	112 (81%)
	Involuntary admissions to psychiatric hospital across **all** help seeking episodes.	Subjects who had at least one event	8 (27%)	47 (34%)
		Total number of involuntary admissions	14	64
		Median [range]	1.5 (1– 3)	1 (1–5)
	Number of nights spent in psychiatric hospital **6 months before** admission	N of subjects with events	22 (73%)	101 (74%)
		Total (total number of nights)	349	1803
		Median [range]	14.5 (6–31)	14.0 (1–176)

Table 4

First Contact at end of First Help-Seeking Episode: Patient characteristics and DUP

	Family and Community resources (N = 57)	Heath Care providers (N = 93)	Police (N = 18)	Total (N = 168)	*p*-value
Age, Years					0.49
Mean (SD)	22.0 (3.9)	22.7 (3.8)	22.5 (3.4)	22.4 (3.8)	
Median [range]	20.9 (16.0, 33.5)	21.6 (16.0, 34.5)	22.5 (16.0, 28.0)	21.5 (16.0, 34.5)	
Sex, n (%)					
Female	18 (31.6)	29 (31.2)	3 (16.7)	50 (29.8)	0.44
Male	39 (68.4)	64 (68.8)	15 (83.3)	118 (68.4)	
First Help-Seeking Timing, n (%)					0.28
Before POPS	9 (15.8)	20 (21.5)	1 (5.6)	30 (17.9)	
After POPS	48 (84.2)	73 (78.5)	17 (94.4)	138 (82.1)	
DUP-demand, days					0.93
Mean (SD)	141.1 (204.2)	144.3 (225.1)	204.9 (307.8)	149.7 (227.8)	
Median [range]	49.0 (0, 846)	52.0 (0, 1059)	58.5 (0, 1153)	52.0 (0,1153.0)	
DUP-total, days					0.14
Mean (SD)	227.0 (270.6)	318.9 (307.0)	323.6 (347.5)	288.3 (301.2)	
Median [range]	95.0 (2.0, 1008.0)	207.0 (9.0, 1189.0)	243.0 (17.0, 1159.0)	160.5 (2, 1189)	
DUP-supply, days					
Mean (SD)	86.0 (188.9)	174.7 (261.7)	118.7 (196.2)	138.6 (235.2)	
Median [range]	15.0 (0, 941.0)	27.0 (0, 1106.0)	23.5 (0, 726)	21.0 (0, 1106.0)	

The first contact made by the initiator during the first help seeking attempt was clustered in the following three groups: 1) health providers (potential prescribers): ER, Hospital, Private Practice, Mental health clinic, Adult and child primary care; 2) Police; 3) Family and Community resources: Friend, Family, School Counsellor, Social Welfare Agency, Mental Health consumers' Organization.