Sources of clinical distress in young people at ultra high risk of psychosis

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**A B S T R A C T**

**Background:** Substantial controversy has been generated since the proposal to include “Attenuated Psychosis Syndrome” in DSM-5, based on research criteria used to identify young people at “ultra high risk” (UHR) for psychosis. The syndrome was ultimately included in the section for further research. The criteria specified that the person experienced attenuated psychotic symptoms (APS) that were sufficiently distressing to warrant clinical attention. Although APS are the main means of determining whether a person meets UHR criteria, clinical experience suggests that such symptoms are often not the main source of clinical distress in this patient group. However, little is known about the sources of distress in the UHR group. We aimed to assess the main sources of clinical distress in UHR patients at the time of referral to a specialized UHR clinic.

**Method:** Sources and intensity of distress in 73 UHR patients were gathered from treating clinicians. The association with transition to psychosis was explored.

**Results:** Of the total sample, 89.04% fulfilled the APS UHR criteria. APS symptoms were reported to be distressing for 58.5% of this subsample, but social and functioning difficulties (78.1%) and depressive symptoms (58.9%) were the highest sources of distress leading UHR patients to seek help. Intensity of distress associated with APS, anxiety symptoms and substance use was associated with transition to psychosis.

**Conclusions:** APS were reported to be distressing for approximately half of UHR patients. The intensity of distress associated to these symptoms may be associated with increased risk for subsequent transition to full threshold psychotic disorder.

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1. Introduction

The prodromal or pre-psychotic phase of psychotic disorders has long been recognised as a period of considerable distress and psychiatric symptomatology characterized by social and functional decline (Yung and McGorry, 1996; Fusar-Poli et al., 2012). Over the last two decades criteria have been developed to prospectively identify young people who may be in this prodromal phase of psychotic disorder (van Os et al., 2005; Yung et al., 2012a; Fusar-Poli et al., 2013), facilitating research and the development of preventative interventions (Yung and McGorry, 1996; Yung et al., 2004; McGorry et al., 2009). These “ultra high risk” (UHR) criteria identify help-seeking young people with a significant decline in functioning presenting with either 1) attenuated psychotic symptoms (APS), 2) brief limited intermittent psychotic symptoms (BLIPS) and/or 3) trait risk factors such as a schizotypal personality disorder or a first degree relative with a psychotic disorder (Yung et al., 2003, 2004). The criteria have been thoroughly validated (Yung et al., 2008) with rates of transition to full psychotic disorder ranging from 35 to 54% over a 12-month period (Yung et al., 2004; Fusar-Poli et al., 2012) and 34.9% over a 10-year period (Nelson et al., 2013).

In the development of DSM-V a new category of “Attenuated Psychosis Syndrome”, based on the UHR criteria, was proposed. This category was ultimately introduced in the section for further research (APA, 2013). The criteria stipulated that attenuated psychotic symptoms (APS) be sufficiently distressing and disabling to the individual to warrant clinical attention (Nelson and Yung, 2011; Fusar-Poli and Yung, 2012). Although most UHR patients typically meet the APS group (about 85% of cases (Yung et al., 2006; Nelson et al., 2013), studies in community samples report a prevalence of about 5% of APS in the general population who are not seeking clinical help and of about 25% in people with common mental health disorders such as anxiety and depression (van Os et al., 2009; Linscott and van Os, 2013). A recent study in the general population estimated that up to 8% of adolescents in their sample (N = 212) met the APS criteria (Kelleher et al., 2012). Only 6.9%
of this subsample reported distress associated with their attenuated psychotic symptoms [Kelleher et al., 2012]. Other studies that explored screening strategies for detection of people at risk of developing psychosis found higher rates of transition to psychotic disorder in young people meeting UHR criteria who were seeking help for general (non-psychotic) psychiatric problems than in a UHR group referred to specialized services for psychosis (Ising et al., 2012; Rietdijk et al., 2012). The distress associated with the APS in the former group was presumably lower than in the latter group, because these symptoms were only detected via screening and were not necessarily a significant source of distress or reason for help-seeking/referral. UHR patients are known to present with a range of non-psychotic psychopathology other than APS, including mood disturbance, anxiety symptoms, personality disturbance, and drug and alcohol problems (Yung et al., 2011; Fusar-Poli et al., 2013). In fact, UHR patients exhibit a considerable degree of other psychiatric outcomes as well as conversion to psychosis (van Os et al., 2001; Addington et al., 2011; Tsuang et al., 2013). The high rates of comorbidities suggest that distress in the UHR group may be associated with a range of presenting symptoms, not just APS, which is consistent with clinical impression at our UHR service and other UHR services (Yung and Nelson, 2011; Nelson, 2014). However, there has been no data published to date on the main sources of distress in the UHR population.

Researching the issue of sources of distress in UHR patients may have implications for the DSM-V “Attenuated Psychosis Syndrome” proposal (Woods et al., 2010; Tsuang et al., 2013). Specifically, it would shed light on whether the proposed Attenuated Psychosis Syndrome would in fact pick up on patients currently seen at UHR clinics or whether the syndrome would target a slightly different group. It is also important to investigate whether distress in relation to APS corresponds to higher risk for transition to psychosis, as identifying predictors of psychosis in the UHR group remains a key research focus (Fusar-Poli et al., 2013). Therefore, in this study we aimed to 1) examine the main sources of clinical distress in UHR patients at the time of referral to our specialized UHR clinic and 2) examine the predictive value of distress associated with APS for transition to psychosis. Based on the clinical observations noted above it was hypothesised that the main source of clinical distress experienced by UHR patients would be non-specific psychopathology rather than APS. We also hypothesised, based on previous findings (Ising et al., 2012; Rietdijk et al., 2012), that the level of distress associated with those non-psychosis related symptoms would be more predictive of transition to psychosis than distress associated to APS alone.

2. Methods

2.1. Participants

Data was obtained from all current Ultra High Risk (UHR) patients seen at the Personal Assessment and Crisis Evaluation (PACE) clinic, Orygen Youth Health (OYH) in Melbourne. The PACE clinic identifies people who are at risk of psychosis and provides them with appropriate treatment and monitoring. Outpatient case managers (OCMs) assess clinical symptoms, distress and diagnosis. In line with the aims of the study, data was acquired from interviews with the patients’ OCM between January to February 2013. Inclusion criteria for patients are being aged between 15 and 24 years, residing in the OYH catchment area (north/north-western suburbs of metropolitan Melbourne) and meeting one or more of the UHR criteria (Yung et al., 2003, 2004): 1) attenuated psychotic symptoms (APS); 2) a group with subthreshold positive psychotic symptoms, 2) brief limited intermittent psychotic symptoms (BLIPS); 3) a group with full threshold psychotic symptoms that have spontaneously resolved (i.e. without treatment) in less than one week, and 3) treat vulnerability for psychotic illness (schizotypal personality disorder or a history of psychosis in a first-degree relative). All UHR groups require that the young person is help-seeking and has experienced a significant drop in functioning or chronic low functioning over the previous year. These criteria are assessed at the time of referral using the Comprehensive Assessment of At-Risk Mental States (CAARMS) (Yung et al., 2005). Exclusion criteria include a previous psychotic episode or an organic cause for presentation.

The study was approved by the local research and ethics committee. All OCMs gave consent to participate in the study. No names or personal information of patients was collected.

2.2. Measures

A semi structured questionnaire-based interview was designed by the authors to systematically assess sociodemographic and clinical variables together with the various sources of clinical distress at the time of referral. Each OCM was interviewed about the main sources of distress of each patient on their current case load at the time they were admitted to the clinic. A maximum of 6 main sources of distress were collected for each patient. The intensity of distress associated with each source of distress was rated by the OCM on a 0–10 Likert scale. The age, gender, diagnosis at the time of admission (primary clinical diagnosis and comorbid conditions based on psychiatric assessment) and UHR intake group were also recorded. Presence and type of past traumatic events (e.g. abuse and neglect), previous suicide attempts and transition to psychosis (number of weeks from admission to transition and psychotic disorder diagnoses) were also recorded from the OCM. All interviews were conducted by the same evaluator (MR-C).

2.3. Statistical analyses

2.3.1. Sample characteristics

Continuous data are presented as means (standard deviation). Discrete variables are presented as frequencies and percentages. Sources of clinical distress, diagnosis and comorbid conditions at the time of admission were grouped into categories to facilitate interpretation of the data. These categories were created on the basis of the interview with the clinicians. A qualitative approach (i.e. content analyses) was used: all sources of distress were recorded and then categorised into 9 categories. Consensus among the investigators was established with regards to grouping of these variables.

Grouping of diagnosis and comorbid conditions resulted into nine categories: UHR alone (no other diagnosis/reason for presentation was reported at the time of admission), personality disorder traits (including borderline personality disorder (BPD), antisocial, schizotypal and narcissistic personality disorder traits), mood disorder (including major depression and dysthymia), anxiety disorder (generalized anxiety, social phobia, posttraumatic stress disorder (PSTD) and obsessive compulsive disorder (OCD)), substance use disorder (alcohol, cannabis, polysubstance abuse and methamphetamine dependence), autism spectrum disorder (ASD), intellectual disability, behavioural difficulties, eating disorder (bulimia and eating disorder non-otherwise specified (NOS)) and bipolar disorder (BP).

2.3.2. Sources of distress

Similarly, the main sources of clinical distress were grouped and coded into 9 categories: APS, Depressive Symptoms, Anxiety, Social and functional difficulties, Substance Abuse, Personality disorder Traits, ASD traits, Trauma history and Eating disorder/Body Image (see Table 1). Nine variables were created accordingly and intensity of distress was calculated for each patient based on the Likert scale’s ratings. The highest rated score was considered when two or more sources of distress (items) on the same category (as grouped in Table 1) were reported. A score of 0 was assigned to patients for whom no source of distress (item) corresponding to a particular category was reported. Intensity scores were also calculated for each individual source of distress (items) included in the main categories (see Table 1). The “main source of distress” for each patient was defined as the clinical source of distress scored with highest intensity. In cases where more
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