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Pathways to care in subjects at high risk for psychotic disorders — A European perspective[☆]

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ABSTRACT

Evidence-based decisions on indicated prevention in early psychosis require large-scale studies on the pathways to care in high-risk subjects. EPOS (The European Prediction of Psychosis Study), a prospective multi-center, naturalistic field study in four European countries (Finland, Germany, The Netherlands and England), was designed to acquire accurate knowledge about pathways to care and delay in obtaining specialized high risk care. Our high risk sample ($n = 233$) reported on average 2.9 help-seeking contacts, with an average delay between onset of relevant problems to initial help-seeking contact of 72.6 weeks, and between initial help-seeking contact and reaching specialized high risk care of 110.9 weeks. This resulted in a total estimated duration of an unrecognized risk for psychosis of 3 ½ years. Across EPOS EU regions, about 90% of care pathway contacts were within professional health care sectors. Between EPOS regions, differences in the pathways parameters including early detection and health-care systems were often very pronounced. High-risk participants who later made transition to a full psychotic disorder had significantly longer delays between initial help-seeking and receiving appropriate interventions. Our study underlines the need for regionally adapted implementation of early detection and intervention programs within respective mental health and health care networks, including enhancing public awareness of early psychosis.

1. Introduction

Retrospective studies of non-affective psychotic disorders have demonstrated long durations of untreated psychosis as well as longer periods of untreated illness prior to the first psychotic episode associated with more negative long-term outcomes (Schaffner et al., 2012). A majority of patients experience a sustained period of non-specific clinical and cognitive symptoms associated with social impairment prior to full psychosis (Häfner et al., 1998) and similar extended pre-psychotic states have been reported in a long-term prospective study (Klosterkötter et al., 2001). Prospective identification of cohorts thought to be at 'high-risk' of transition has consequently become the focus of most current clinical and research strategies targeting the pre-psychotic period with their potential to improve outcomes, prevent or reduce transition levels, and reduce the burden of patients, families and society alike (McGorry et al., 2009). Early studies resulted in three major approaches to profiling high risk subjects (Miller et al., 2003; Yung et al., 2005; Schultze-Lutter et al., 2007), and subsequent research focus on comparing the efficacy of treatment models.

In line with first episode services successfully targeting the duration of untreated psychosis, i.e. the period between the onset of frank psychosis and receiving an adequate treatment (Bird et al., 2010),

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early detection and intervention services for subjects at high risk employ standardized criteria to identify patients and offer appropriate interventions the earliest, providing them with specialized stage-specific treatment, and reducing overall societal costs (Phillips et al., 2009). Over the past 20 years, clinical and research programs have been established in America, Australasia, and Europe, with evidence supporting an overall positive impact (Marshall and Rathbone, 2011). Pharmacological, psychological and nutritional interventions to prevent or delay transition to psychosis in these cohorts have resulted in modest effects (Stafford et al 2013) and a recent major review on current indicated early detection and intervention lists meaningful prediction criteria, significant transition rates, feasible and effective preventative interventions, and potential cost reductions among the benefits of providing such services (Fusar-Poli et al., 2013).

Despite these developments and a high number ongoing studies of determinants impacting on the duration of untreated psychosis and pathways to care in first episode patients (Anderson et al. 2010; Schaffner et al., 2012), little is currently known about factors affecting the duration of untreated illness prior to first episode, and the implications for those who may be at high risk of developing psychosis. One can assume that both the quality and efficacy of early detection and intervention strategies and services could be enhanced by gaining and implementing more accurate knowledge about the pathways to care and possible delays in obtaining appropriate treatment (Lincoln and McGorry, 1995; Larsen et al., 1998). Both, a recent meta-analysis of initiatives that aim to reduce the duration of untreated psychosis in first episode psychosis and a study comparing treatment delays in the duration of untreated illness and duration of untreated psychosis at a five year follow-up period suggest that early detection and intervention approaches targeting the duration of untreated illness in the high risk period may have a positive impact, particularly if they are supplemented by public health education strategies (Lloyd-Evans et al., 2011; Norman et al., 2011).

To date, data on pathways to care in subjects at high risk for psychosis have been obtained in studies from Australia, Switzerland and Korea with available results pointing to a typical mean of 2.4 prior help seeking contacts and average times of 41.4 (Korea) and 124 (Switzerland) weeks between a first contact with any relevant care agent and a referral to specialized care. The Australian study reports a mean of 85.8 weeks from onset of relevant problems to initial help-seeking, and therefore allows for the estimation of a measure roughly comparable to the duration of untreated psychosis first episode psychosis of “approximately 2.5 years (127 weeks)” duration of untreated risk for psychosis in symptomatic terms.

These studies demonstrate a progression from general health care providers, as e.g. general practitioners, into psychiatric health care for contacts made in urban Anglo-European areas (Philips et al, 1999; Platz et al, 2006). In demographically different settings as e.g. in highly industrialized urban areas of East Asia, however, other patterns of referral emphasizing the role of family and the internet may hold true, pointing to a high contextual sensitivity of such measures (Shin et al, 2010).

Studies from Canada, Germany, the US and the UK on pathways to care or closely related topics include information on referral sources and prior treatment of subjects at high risk of psychosis, with treatment generally focusing on pharmacotherapy and psychotherapy applied to individual help-seeking subjects (Köhn et al., 2004; Addington et al, 2008; Cadenhead et al, 2010; Murphy et al, 2010).

Most of these studies are rely on similar preventative strategies with specialized psychiatric services aiming to identify and offer appropriate professional interventions to high risk subjects prior to any development of a first episode psychotic disorder. They tend to be comparable in advocating public health awareness campaigns, and employing robust diagnostic procedures and early intervention strategies (McGlashan et al., 2007; McGorry et al, 2009).

Despite these efforts, current knowledge of pathways to care for those at high risk of psychosis remains relatively sparse and inadequate to inform improvements to existing services and the development of new care pathways. In addition, assumptions regarding negative effects of prolonged durations of untreated illness or dysfunctional pathways to care remain to be empirically proven. To this end a major aim of the European Prediction of Psychosis Study (EPOS) was to investigate the pathways to care in a large sample of subjects across six regions in four European countries to enable an informed critical appraisal of the reasons for and impact of delay in help-seeking high risk subjects alongside the potential importance of early detection and intervention service provision in discrete settings (Klosterkötter et al., 2005).

For the purposes of this report we restricted the analysis to a limited number of relevant topics with the major focus on key pathways to care indicators associated with delay in receiving appropriate care. Number of help-seeking events, initial help-seeking delay (time from onset of at-risk criteria to first help-seeking contact), and treatment delay (time between first help-seeking contact and receiving appropriate treatment) were examined for this purpose. In addition, we calculated an estimation of the duration of an unrecognized risk for psychosis, defined as a composite of the latter two indicators.

With regard to these key indicators, we report:

(1) (Non-statistical) comparisons with previous pathways to care data from Switzerland and Australia to see whether or not the EPOS results are comparable with known patterns of service provisions and delays, and if any general conclusions could be drawn regarding improvements of early detection and intervention in high risk subjects.
(2) Statistical comparisons between the four participating European regions (Finland, Germany, The Netherlands and England) for significant regional differences. This would enable discussion in regard to the further development of new and existing early detection and intervention services for people at high risk for psychosis.
(3) Statistical comparisons for delays between those high risk subjects who did and did not make transition to psychosis after the 2nd follow-up (18 months follow-up) time-point.

A secondary focus of this analysis was on the types of existing service provision, and health professionals seen for subjects at high risk across the different European regions.

Here we analyzed:

(4) Statistical comparisons in service provision and use by the high risk sample subjects prior to their inclusion into EPOS. We predicted significant differences in the types and personnel of the respective regional health care systems possibly due to both, their intrinsic regional features and the peculiar set-up and recruitment strategies of the early detection and intervention services at hand. As with the other key indicators, our focus was less on differences in service availability and receipt. On this basis, first conclusions could be drawn for the further development of existing and implementation of new early detection and intervention services for people at high risk for psychosis in different health care cultures and settings.
(5) Additionally we examined previous formal and informal help-seeking contacts with non-health care professionals in our high risk subjects. Identifying those whom high risk patients may turn to in distress would allow for targeted approaches to relevant training and education (e.g. public awareness campaigns in schools).

Other relevant topics of our pathway research including subjects' mental health knowledge and health care attitudes, social support received by professional and non-professional relevant others, the symptoms presented and treatments received at different service points were beyond the scope of the present paper.