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# Prediction of self-stigma in early psychosis: 3-Year follow-up of the randomized-controlled trial on extended early intervention

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#### ABSTRACT

*Background:* Self-stigma represents a major barrier to recovery in people with psychotic disorders but is understudied in early illness stage. Longitudinal investigation of prediction for self-stigma is scarce and none is conducted in early psychosis. We aimed to prospectively examine baseline predictors of self-stigma in early psychosis patients in the context of a 3-year follow-up of a randomized-controlled trial (RCT) comparing 1-year extension of early intervention (EI) with step-down psychiatric care for first-episode psychosis (FEP).

Method: One hundred sixty Chinese patients were recruited from a specialized EI program for FEP in Hong Kong after they had completed this 2-year EI service, and underwent a 12-month RCT. Participants were followed up and reassessed 3 years after inclusion to the trial. Comprehensive evaluation encompassing clinical, functional, subjective quality of life and treatment-related variables were conducted. Data analysis was based on 136 participants who completed self-stigma assessment at 3-year follow-up.

Results: Fifty patients (36.8%) had moderate to high levels of self-stigma at 3-year follow-up. Multivariate regression analysis revealed that female gender, prior psychiatric hospitalization, longer duration of untreated psychosis and greater positive symptom severity at study intake independently predicted self-stigma at the end of 3-year study period.

Conclusion: Our results of more than one-third of early psychosis patients experienced significant self-stigma underscore the clinical needs for early identification and intervention of self-stigmatization in the initial years of psychotic illness. Further research is warranted to clarify prediction profile and longitudinal course of self-stigma in the early illness phase.

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#### 1. Introduction

Psychotic disorders are severe mental illnesses associated with significant functional disability and huge societal costs. Evidence indicates that stigmatization toward people with psychotic disorders is a highly pervasive phenomenon across communities (Thornicroft et al., 2009; Wood et al., 2014), particularly in Chinese societies (Lee et al., 2005; Tsang et al., 2007; Yang, 2007). A recent review further confirmed high prevalence of personal stigma experienced by people with psychotic disorders (Gerlinger et al., 2013). Among various forms of stigma, self-stigma has been identified as a major impediment to recovery (Link et al., 2001; Fung et al., 2007) and has received increasing attention in recent psychiatric research. Briefly, self-stigma refers to a process in

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which individuals with mental illness accept and internalize socially endorsed negative stereotypes of the illness (Corrigan and Watson, 2002). This negative labeling may cause self-esteem decrement, maladaptive avoidant coping and reduced motivation in pursuit of goals, and hence resulting in social alienation and restriction of life opportunities (Link et al., 1989, 2001; Corrigan et al., 2006, 2009). In fact, literature has demonstrated that self-stigma was associated with negative outcomes in patients with psychotic disorders (Livingston and Boyd, 2010; Gerlinger et al., 2013) including reduction in self-esteem, self-efficacy and hope (Ritsher and Phelan, 2004; Lysaker et al., 2007a; Vauth et al., 2007; Yanos et al., 2008; Staring et al., 2009; Young and Ng, 2016), depression (Ritsher and Phelan, 2004; Staring et al., 2009; Sibitz et al., 2011; Park et al., 2013; Schrank et al., 2014), increased positive symptom severity (Cavelti et al., 2014), poorer subjective quality of life (QoL) (Staring et al., 2009; Park et al., 2013; Chan and Mak, 2014; Mosanya et al., 2014; Lien et al., 2016; Young and Ng, 2016), worse social and vocational functioning (Lysaker et al., 2007b; Munoz et al., 2011; Yanos et al., 2010,

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2012; Cavelti et al., 2014), and poorer treatment adherence (Fung et al., 2008; Tsang et al., 2010).

Of note, most previous research on self-stigma in psychotic disorders focused on patients with chronic illness. Factors associated with selfstigma in the early stage of illness are understudied. Nonetheless, this is of significant clinical implication as self-stigma emerging in the initial illness phase would likely be more amenable to intervention. Until now, there are four published studies (Birchwood et al., 2006; Tarrier et al., 2007; Norman et al., 2011; Chen et al., 2016) examining personal stigma in patients with early psychosis. Two of them investigated perceived stigma instead of self-stigma in first-episode psychosis (FEP) (Birchwood et al., 2006; Tarrier et al., 2007), with one showing that patients with social anxiety had greater perceived stigma and fear of negative evaluation (Birchwood et al., 2006). One recent study on early psychosis patients replicated findings observed in chronic samples and found that self-stigmatization was related to lower levels of psychological well-being (Norman et al., 2011). Our previous report revealed that more severe perceived stigma and greater concern of losing face were associated with higher level of self-stigma in a small sample of FEP patients (Chen et al., 2016). Alternatively, thus far, few longitudinal studies have been conducted to examine predictors of self-stigma in psychotic disorders and there is none in early psychosis. Given the current focus on early intervention for psychosis alongside a paucity of data regarding predictors, in particular clinical determinants, of self-stigma in early psychosis, it is thus recommended for prospective investigation of prediction for self-stigma in the early phase of psychotic illness (Gerlinger et al., 2013).

In Hong Kong (HK), a territory-wide, publicly-funded specialized treatment program for young people with FEP, namely Early Assessment Service for Young People with Psychosis (EASY), has been established since 2001 (Chung and Chen, 2013). The program provided comprehensive evaluation and 2-year phase-specific early intervention (EI) to FEP patients aged 15-25 years, who were each assigned with a case manager with provision of protocol-based psychosocial interventions (So, 2013). Patients were transferred to a transitional step-down clinic in the third year of treatment with no case management provided, followed by generic psychiatric service for continuous care. We have previously conducted a 3-year follow-up of a randomized-controlled trial (RCT) evaluating the efficacy of a 1-year extension of EI (Extended EI or 3-year EI) vs. step-down psychiatric care (SC or 2-year EI) in clinical and functional outcome improvement in a cohort of Chinese FEP patients who had completed 2-year treatment in EASY program (Chang et al., 2015; Chang et al., 2017). This is the first RCT follow-up study examining sustainability of therapeutic benefits of EI service for FEP on clinical and functional outcomes with its treatment period extended beyond 2 years. Results of this study showed that superior effects achieved by Extended EI could not be maintained after termination of the specialized service (Chang et al., 2017).

In the current report, we sought to examine the rate and predictors of self-stigma in early psychosis patients in the context of this 3-year RCT follow-up study. Comprehensive assessments encompassing clinical, functional, subjective QoL and treatment-related variables were included to enable better clarification of baseline prediction profile for self-stigma at 3-year follow-up.

#### 2. Methods

#### 2.1. Participants and setting

The current investigation was based on a 3-year follow-up of a single-blind RCT comparing a 1-year extension of specialized EI (a 3-year EI service) with a step-down care (a 2-year EI service) in FEP patients who had received 2-year treatment from EASY program. Details of the study methodology have been reported elsewhere (Chang et al., 2015, 2017). Briefly, 160 patients with DSM-IV diagnosis of psychotic disorder were recruited from EASY program upon completion of 2-year EI care,

randomly allocated to Extended EI (n = 82) or SC (n = 78), and underwent 1-year clinical trial (Chang et al., 2015). Patients with substance-induced psychosis, psychotic disorder due to general medical condition or learning disability were excluded. In Extended EI group, an additional year of specialized case-management was delivered by a trained case manager, who took over the cases from EASY program and coordinated treatments with clinicians, allied health professionals and community centers. Case management provided closely aligned with EASY treatment protocols and specifically focused on functional improvement, with a view to facilitating participants to enhance social networks, resume leisure pursuits and return to work. Psychoeducation, supportive care and counseling on stress coping were also offered to participants' caregivers by the case manager. Participants randomized to SC group received medical follow-up with limited community support focusing primarily on crisis intervention, and no case management was provided. Participants from both treatment groups were managed by psychiatrists from their respective EASY clinical teams and did not differ in the intensity of psychiatric follow-up, prescription of antipsychotic medications, and availability of psychosocial interventions and community-based services (Chang et al., 2015). Participants were followed up and re-interviewed 2 and 3 years after inclusion to the trial (Chang et al., 2017).

In this report, we focused on examining baseline predictors of self-stigma in 136 participants of the initial RCT cohort who had completed self-stigma assessment at 3-year follow-up. The study was approved by the local institutional review boards. All participants provided written informed consent. For those under 18 years old, consent was also obtained from a parent or guardian.

#### 2.2. Assessments

Diagnostic ascertainment of each participant was based on verifying all available information including Chinese-bilingual Structured Clinical Interview for DSM-IV (CB-SCID, So et al., 2003) conducted at study intake (baseline, i.e. upon completion of 2-year EASY care), 1- and 3year follow-up, medical records and informant histories. Duration of untreated psychosis (DUP, i.e., time interval between onset of positive symptoms and treatment initiation) and age of psychosis onset were determined using the Interview for the Retrospective Assessment of the Onset of Schizophrenia (IRAOS, Hafner et al., 1992). Psychopathology was evaluated by Positive and Negative Syndrome Scale (PANSS, Kay et al., 1987) and Calgary Depression Scale (CDS, Addington et al., 1990). Antipsychotic-induced extrapyramidal side-effects including Parkinsonism features, dyskinesia and akathisia were measured using Simpson-Angus Scale (SAS, Simpson and Angus, 1970), Abnormal Involuntary Movement Scale (AIMS, Guy, 1976), and Barnes Akathisia Rating Scale (BARS, Barnes, 1989) respectively. A self-administered 10-item Drug Attitude Inventory (DAI-10, Awad, 1993) was employed to assess participants' attitude toward antipsychotic treatment, with higher scores indicating more positive attitude. Functional levels were measured by Social and Occupational Functioning Assessment Scale (SOFAS, Goldman et al., 1992) and Role Functioning Scale (RFS, Goodman et al., 1993). A self-report Chinese version of Medical Outcome Study 36 Item Short Form Health Survey (SF-36, Ware and Sherbourne, 1992, Lam et al., 1998) was used to measure participants' subjective health-related quality of life (QoL). The SF-36 mental and physical component summary (MCS and PCS) scores were calculated as primary measures of subjective QoL (McHorney et al., 1993; Kwong et al., 2017). Assessments on symptom severity, treatment characteristics and subjective QoL were conducted at baseline, 1, 2 and 3-year follow-up. Functional assessment was administered at baseline, and 6 months, 1, 2 and 3 years after study entry.

Self-Stigma Scale-Short Form (SSS-S) (Mak and Cheung, 2010) was administered at 3-year follow-up to measure the degree of stigma internalization in early psychosis patients. It is a 9-item self-rated questionnaire covering affective, cognitive, and behavioral dimensions of self-

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