



Potential stigma associated with inclusion of the psychosis risk syndrome in the DSM-V: An empirical question

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ABSTRACT

While the “clinical high-risk state” for psychosis has demonstrated good reliability and fair predictive validity for psychotic disorders, over 50% of identified subjects do not progress to psychosis. Despite the benefits that early detection and treatment might offer, debate concerning the official inclusion of a “psychosis risk syndrome” in the upcoming DSM-V frequently involves concerns about the impact of stigma on patients, families and institutions. We add to this debate by providing an analysis of the theoretical and empirical stigma literature to evaluate the potential effects of stigma associated with the psychosis risk syndrome. Theorists’ conceptualizations of how stigma exerts its negative effects emphasize internalization of pejorative societal stereotypes (‘self-stigma’), negative emotional reactions, harmful behavioral coping strategies, and structural discrimination as key mechanisms. Studies assessing the comparative effects of symptomatic behavior when compared with a psychiatric diagnosis label in predicting rejecting social attitudes indicate that treating symptomatic behaviors is likely to diminish overall stigma. However, any publically held ‘preexisting conceptions’ about what a psychosis risk syndrome means are still likely to exert negative effects. Additionally, particular features of this syndrome—that it occurs during adolescence when identity formation may be in flux— may also shape manifestations of stigma. Utilizing other well-established ‘at-risk’ conditions (e.g., genetic susceptibility) to model potential discrimination for this syndrome, we suggest that future discrimination is likely to occur in insurance and family domains. We conclude by proposing stigma measurement strategies, including recommending that field trials prior to DSM-V adopt systematic measures to assess any stigma that this psychosis risk syndrome might confer via future community use.

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1. Introduction

Schizophrenia, a chronic and severe mental illness characterized by the presence of hallucinations, delusions, and potential lifelong impairment, has been identified as the 9th leading cause of disability worldwide (WHO, 2008). Because the onset of schizophrenia is preceded in 80% of cases by “prodromal” features (e.g., subclinical psychotic symptoms, mood symptoms,

and social withdrawal; Hafner et al., 1998) the development of a diagnosis to accurately detect a “clinical high-risk state” for psychosis has great implications in forestalling the morbidity and reducing the public health burden associated with this and other psychotic disorders. The psychosis risk syndrome has been operationalized as subthreshold psychotic symptoms, primarily in attenuated form (Miller et al., 2003). Use of this classification for identification and treatment of clinical high risk patients (consisting of antipsychotic medication and cognitive-behavioral therapy, McGorry et al., 2002, or antipsychotic medication only; McGlashan et al., 2004) in initial randomized clinical trials has

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indicated the possibility of reducing prevalence of psychotic disorders by delaying or preventing onset of psychosis among those treated.

Despite the potential benefits such a diagnosis might offer, a debate exists concerning the official inclusion of a psychosis risk syndrome in the upcoming Diagnostic and Statistical Manual for Mental Disorders (DSM-V) to be published in 2012. While an NIH-funded consortium of eight prodromal study sites has provided evidence as to the reliability (*Kappas* > .80 at each site) and fair predictive validity of the psychosis risk syndrome (approximately 35% of patients develop psychosis within 2.5 years. Cannon et al, 2008 to support inclusion of this syndrome in DSM-V, over 50% of identified subjects may not progress to psychosis. Because of the syndrome's uncertain long-term course, and because diagnosis will typically be made with young adults who are in the early stages of their identity development, concerns exist as to the potential impact of stigma on patients, families, and institutions (Corcoran et al., 2005; McGorry et al., 2001). Further, given that community cohort studies report the lifetime prevalence of having at least one psychotic symptom to be 10–20% among respondents (Yung et al., 2006), any stigma attached to a “psychosis risk” diagnosis may potentially affect a great number of people.

Despite the possibility that this syndrome may be incorporated into DSM-V, no studies to date have systematically examined how any potential stigma induced by the label of psychosis risk might affect identified patients, nor are there any reviews of the existent theoretical and empirical literature on stigma which may inform this empirical question. Prior conceptual work has outlined the effects that stigma might have upon individuals identified with this syndrome by drawing upon ethical perspectives and research on other ‘at-risk’ states (Corcoran et al., 2005). We seek to add to this debate by reviewing the literature on stigma to better evaluate its potential effects on individuals who are labeled as having the psychosis risk syndrome and to recommend specific methodologies to study this construct. Rather than offering a systematic review of this literature, we provide an analysis from the perspective of specialists in stigma theory and measurement. We first ascertain what domains within the multidimensional construct of stigma are most relevant and identify the possible mechanisms by which stigma might impact individuals labeled as ‘at-risk’ for psychosis. Next, we clarify the potential relative contributions of stigma from symptomatic behaviors versus that received from labeling. We further examine how issues particular to the psychosis risk syndrome—i.e., its occurrence at a relatively early developmental stage, and its status as a ‘high-risk’ state that might elicit common forms of discrimination seen with other well-established ‘at-risk’ conditions (e.g., genetic susceptibility)—may further inform our understanding of these possible stigma mechanisms. We conclude by recommending strategies to measure any possible risk of stigma that the official creation of a psychosis risk diagnosis might confer.

2. Defining stigma

Conceptualizations of stigma have varied greatly from frameworks emphasizing internal psychological processes to more complex formulations incorporating evolutionary forces, institutional policies, and sociopolitical structures (for reviews, see Yang et al., 2008a,b; Yang et al., 2007). We

focus our discussion on the stigma definitions and processes that most directly illustrate how an official psychosis risk designation might impact identified patients. In his classic formulation, Goffman (1963) defines stigma as “an attribute that is deeply discrediting” that reduces the bearer “from a whole and usual person to a tainted, discounted one” (p. 3). Subsequent social psychological definitions describe stigma as consisting of a ‘mark’ that—with its associated negative meanings—are seen to “engulf” how the person is perceived by society (Jones et al., 1984). These definitions emphasize the centrality of stereotypes and how these societal perceptions devalue an individual's social identity in a particular context (Crocker et al., 1998).

Expanding from notions of stigma as an attribute and stereotype, definitions have more recently encompassed interrelated stigma components (Link and Phelan, 2001), of which several might usefully describe any possible effects of a psychosis risk syndrome. Link and Phelan first incorporate similar stigma processes to other theorists, such as *labeling* (when people distinguish a human difference as significant and assign it a label), *stereotyping* (when beliefs link labeled persons to negative characteristics) and *cognitive separation* (when distinction of ‘us’/‘normals’ from ‘them’/‘deviants’ is achieved). Link and Phelan also incorporate a novel set of processes. *Emotional reactions* (added in Link et al., 2004) include the affective responses experienced by both stigmatizers (e.g., fear) and the stigmatized (e.g., shame). *Status loss and discrimination* result when labeled individuals experience either devaluation or unfair treatment. Discrimination may occur through person-to-person forms (i.e., individual-level discrimination such as social rejection) or when institutional practices disadvantage stigmatized groups (i.e., structural discrimination such as denial of insurance due to pre-existing illness; Corrigan et al., 2004). Lastly, Link and Phelan emphasize that the stigma process relies on the use of social, economic, and political *power* that imbues the foregoing stigma components with discriminatory consequences. From these formulations, we highlight processes involving awareness of societal stereotypes (and importantly, its application to the self via “internalized stigma” or “self-stigma” described below) and forms of structural discrimination as potential mechanisms by which stigma might affect individuals identified as “at-risk” for psychosis.

2.1. Models which inform how stigma can impact individuals

Theorists' conceptualizations of how stigma exerts its negative effects on individuals (for extensive reviews, see Major et al., 2004; Steele et al., 2002) further illuminate possible mechanisms by which individuals identified as ‘at-risk’ for psychosis might be affected. In addition to conceptualizing stigma as occurring when the mark links an individual via attributional processes to undesirable characteristics (Jones et al., 1984), subsequent models have incorporated the response of individuals to stigma; e.g., maintaining self-esteem through cognitive coping strategies (Crocker et al., 1998; Major and O'Brien, 2005). A key contribution of these formulations is that both stigmatizers and the stigmatized may *internalize* negative stereotypes (Steele et al., 2002). Internalized stigma takes place via stigmatized individuals themselves once they become aware of mental illness stereotypes and apply these stereotypes to themselves in psychologically harmful ways (Ritsher and Phelan,

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