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Potential Stigma Associated with Inclusion of the Psychosis Risk Syndrome in the DSM-V: An Empirical Question

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Abstract

While the “high-risk state” for psychosis (or “prodrome”) has demonstrated good reliability and predictive validity for conversion to psychotic disorders, over 50% of identified subjects may 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 the threat of stigma’s impacts to patients, families, and institutions. We advance this debate by providing a focal analysis of the extensive theoretical and empirical stigma literature to better articulate stigma’s potential effects upon ‘prodromal’ individuals. 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 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 is in flux—further 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 may likely 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.
Keywords

stigma; psychosis; prodrome; discrimination; adolescents; schizophrenia

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, 2004). 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 “high-risk state” for psychosis (or “prodrome”) has great implications in forestalling the morbidity and reducing the public health burden associated with this illness. This psychosis risk syndrome has thus been classified as subthreshold psychotic symptoms that fulfill at least one of three criteria: attenuated positive symptoms, brief intermittent psychotic symptoms, and/or functional decline in the context of genetic risk (Miller et al, 2003). Use of this classification for identification and treatment of ‘at-risk’ for psychosis 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 indicated the possibility of reducing prevalence of psychotic disorders by delaying onset of conversion to psychosis among those treated.

Despite the great 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 a NIH-funded consortium of eight prodromal study sites has provided key evidence such as good reliability (Kappas > .80 at each site) and predictive validity of the psychosis risk syndrome (approximately 40% of individuals convert to psychosis within 2.5 years of identification; Woods et al, 2009) to support inclusion of this syndrome in DSM-V, over 50% of identified subjects may not progress to psychosis. Because of the illness’ uncertain long-term course, and because diagnosis will typically be made with young adults who are in the early stages of their identity development, the risk of stigma’s impacts across patients, families, and institutions (including future insurability) arises repeatedly (Corcoran, Malaspina & Hercher, 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 strong possibility of this syndrome being incorporated into DSM-V, no studies to date have systematically examined how any potential stigma induced by the psychosis risk syndrome impacts identified patients, nor have any conceptual reviews applied the extensive theoretical and empirical stigma literature to describe the ‘high-risk’ state for psychosis. 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’ disease states (Corcoran et al., 2005). We seek to advance this debate by drawing upon a well-developed stigma literature to better articulate stigma’s potential effects upon individuals ‘at-risk’ for psychosis and to recommend specific methodologies to study this harmful construct. Rather than offering a systematic review of this literature, we provide a focal 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 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 share common forms of discrimination with other well-established ‘at-risk’ conditions (e.g., genetic susceptibility)—further modify our understanding of these possible stigma mechanisms. We conclude by recommending strategies to measure any possible risk of stigma that a psychosis risk syndrome 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, Kleinman, & Cho, 2008; 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, Major, & Steele, 1998).

Expanding from notions of stigma as an attribute and stereotype, definitions have more recently encompassed interrelated stigma components (Link & J. C. 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 complete distinction of ‘us’/‘normals’ from ‘them’/‘deviants’ is achieved). Link and Phelan also incorporate a novel set of processes. Emotional reactions (added in Link, Yang, J. C. Phelan, & Collins, 2004) include the affective responses experienced by both stigmatizers (e.g., fear) and the stigmatized (e.g., shame). Status loss and discrimination results 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, Markowitz, & Watson, 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 even more 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 by which Stigma Impacts Individuals

Theorists’ conceptualizations of how stigma exerts its negative effects on individuals (for extensive reviews, see Major, S. McCoy, Kaiser, & Quinton, 2004; Steele, Spencer, & Aronson, 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.,
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 through stigmatized individuals themselves once they become aware of mental illness stereotypes and apply these stereotypes to themselves in psychologically harmful ways (Ritsher & J. C. Phelan, 2004). Corrigan et al (2006) have further proposed ‘self-stigma’ as a process spanning initial awareness of stereotypes that leads to its endorsement and ultimately, application of the stereotype to one’s self-evaluation.

Of particular significance to how stigma impacts people with psychiatric illness is the sociological model of “labeling theory”. Based on symbolic interactionism (Mead, 1934), this concept proposes that social responses to deviant behaviors (e.g., hears voices and talks to oneself) are continuously shaped by shared cultural languages and symbols (that ‘crazy’ person is ‘erratic and should be locked up’). Self-conceptions then arise from perceptions of others’ views and responses (Markowitz, 2005), thus socializing an individual into ‘role identities’ (i.e., being ‘mentally ill’) which are accompanied with behavioral expectations (i.e., disability). Link, Cullen, Struening, Shrout, & Dohrenwend (1989) proposed a ‘Modified Labeling Theory’ that individuals as part of everyday socialization internalize notions of what it means to be labeled with mental illness. These internalized conceptions consist of the degree that community members believe that people with psychiatric illness will be devalued and discriminated against. Since official labeling takes place through contact with psychiatric treatment, expectations of community devaluation now become personally relevant. According to Link et al, two harmful ways that labeled individuals may respond to anticipated rejection are: 1) secrecy or concealing one’s treatment history and; 2) withdrawal or limiting contact to those accepting of one’s condition. Prior literature has shown that labeling-induced mental illness stigma is associated with lower self-esteem (Fung et al., 2007; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001), demoralization (Link, Mirotznik, & Cullen, 1991), depressive symptoms (Link et al., 1991; Ritsher & Phelan, 2004), less adherence with treatment (Fung et al., 2007), constricted social networks (Link et al., 1989), and reduced social integration (P. N. Prince & C. R. Prince, 2002). Such effects also limit life chances through increased unemployment (Link et al., 1991) and loss of housing opportunities (Page, 1977), which are then seen to increase vulnerability to future psychiatric relapse.

These models illustrate the process of ‘self-stigma’ (Corrigan et al., 2006) to explain how individuals with mental illness might internalize pejorative societal stereotypes and experience potential negative emotional reactions (Link et al., 2004). Further, the harmful behavioral coping strategies employed by individuals with psychiatric illness to minimize potential impacts of being classified as ‘mentally ill’ and to avoid perceived anticipated rejection comprise another key stigma mechanism (Link et al., 1989). We highlight the processes of ‘internalized stigma’ and behavioral stigma coping strategies as possible mechanisms by which stigma might affect individuals identified as ‘high-risk’ for psychosis.

3. The Effects of Labeling Versus Symptoms in Stigma Formation

While the harmful effects of mental illness labeling are supported by considerable empirical evidence, critics have offered counterpoints. First, psychiatric patients have reported relief that a label can explain symptoms and validate their experiences (Hayne, 2003). From a public health perspective, early identification and labeling might benefit patients ‘at-risk’ for psychosis by eliciting helping responses and resulting in swift, targeted treatment (McGorry et al., 2002), effectively treating ‘prodromal’ symptoms to prevent symptom exacerbation and thereby decreasing stigma (McGorry, Yung, & Phillips, 2001). A closely related argument is that patients who might be identified as at a ‘high-risk state’ for psychosis are
already suffering from marked psychiatric disturbances (e.g., subthreshold psychotic symptoms, dysphoria, anxiety, and social withdrawal; Woods et al., 2009) that evoke stigma in and of themselves (Wong et al., 2009). This perspective encapsulates a key criticism of ‘labeling theory’; that negative societal reactions are far more closely linked to symptomatic behavior than by stereotypes associated with mental illness labeling (Clausen, 1981). From this viewpoint, any additional stigma conferred by being identified as ‘at-risk’ for psychosis to such symptomatic individuals may be minimal in comparison to or outweighed by the benefits of effectively reducing symptoms (and thus, any resultant stigma).

To address this issue, we refer to a substantial accumulation of experimental or quasi-experimental studies that assess the relative contribution that a target individual’s disruptive behavior (e.g., as varied in a vignette) has in predicting community members’ rejecting social attitudes when compared with the impacts of a psychiatric label. A comprehensive earlier review (Link, Cullen, Frank, & Wozniak, 1987) states that ten of twelve studies reported that behavior had a statistically significant effect that was more robust than effects of labeling. This general pattern— that behaviors more consistently shape community members’ rejecting responses than labeling—has been subsequently replicated (Murrie, Cornell, & W. K. McCoy, 2005). However, labeling effects continue to contribute directly to rejecting attitudes; six of the twelve studies reviewed by Link et al also found at least some direct negative effects of labeling on stigmatization. More critically, Link et al’s (1987) seminal work revealed that the simple assessment of labeling utilized in this prior set of studies (which neglected to measure the ‘array of beliefs’ commonly evoked by the label) inadequately gauged labeling’s effects on rejecting attitudes. That is, it is not merely the label itself but the activated ‘set of preexisting conceptions’ that shape rejecting responses. Only when Link et al included a measure of ‘preexisting beliefs’ (i.e., perceived dangerousness of people with mental illness) did strong labeling effects emerge; i.e., solely among those who already endorsed stereotypes of dangerousness did mental illness labels amplify rejecting attitudes.

Such work is critical to frame any potential stigmatizing effects of a psychosis risk syndrome in comparison with stigma reduction resulting from symptom treatment. Although ameliorating symptomatic behaviors is also likely to diminish stigma, any publically-held ‘preexisting conceptions’ about what a psychosis risk syndrome means for interpreting a person’s behavior may quite possibly exert negative effects. It is therefore imperative to empirically assess general community members’ preexisting beliefs concerning a psychosis risk syndrome to determine any possible impacts of this designation. Since the distinction between susceptibility and a disease itself is subtle and may not be fully grasped by the public, vulnerability may be misunderstood as a “quasi-diagnosis” (Corcoran et al., 2005) and indistinguishable from labels of “schizophrenia” or “severe mental illness”. The ‘psychosis’ label has been shown to elicit an inability to share one’s reality with others, use of the ‘crazy’ label, and fear that recovery is unattainable (Lally, 1989). Given that the label of “schizophrenia” evokes the most negative stereotypes (e.g., dangerous), emotional reactions (e.g., fear), social distance, and pessimism that such patients “will never recover” among all mental disorders (Angermeyer & Matschinger, 2003; Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000; Link, J. C. Phelan, Bresnahan, Stueve, & Pescosolido, 1999), it is crucial to ascertain to what degree the public might link these attributes to individuals ‘at-risk’ for psychosis. In addition to shaping community members’ reactions to such individuals (and hence, person-to-person forms of discrimination), the content and valence of these stereotypes are predicted to underlie any possible key stigma processes such as those we have identified—i.e., the ‘self-stigma’, emotional reactions, and adoption of behavioral coping responses—that individuals ‘at-risk’ for psychosis might experience.
4. Stigma of a Psychosis Risk Syndrome

These potential stigma dimensions and mechanisms may be further shaped by particular features of a psychosis risk syndrome—that it occurs during adolescence when identity formation is in flux and that it is a ‘high-risk’ condition that might share characteristics with other ‘at-risk’ disease states. We review these issues—and their possible impacts on potential stigma—below.

4.1 Stigma and Labeling among Adolescents

Age-related aspects of a psychosis risk syndrome may shape any possible stigma among patients as diagnosis is likely to take place during adolescence (around eighteen years of age; Woods et al., 2009), a developmental period characterized by identity consolidation. Young adults must negotiate developmental goals, including strengthening an autonomous self-concept, attaining educational milestones, and forming social networks. Mental illness ‘labeling’ may interfere with the acquisition of ‘personal assets’ or competencies needed for successful passage to adulthood (Zarrett & Eccles, 2006). Given that adolescents’ self-concepts are less well-formed, being labeled with severe mental illness has the potential to permeate one’s social identity and threaten a sense of normalcy (Wisdom & Green, 2004; Yang et al., 2007). Lally (1989) proposes that one’s self-concept becomes transformed via a process whereby illness roles become central to an individual’s identity and valued social roles diminish until only a ‘chronically ill’ role remains (McCay et al., 2007).

Unfortunately, both adult and adolescent surveys of public attitudes indicate that adolescents with mental illness are just as likely to be viewed as unfavorably as their adult counterparts. For example, approximately 45% of adults sampled in the nationally representative General Social Survey agreed that “getting mental health treatment would make a child an outsider at school” (Pescosolido, Perry, Martin, McLeod, & Jensen, 2007). This adult sample also perceived children with ADHD or depression to be significantly more dangerous than others, and this perception increased five-fold when participants independently labeled children as “mentally ill” (Pescosolido, Fettes, Martin, Monahan, & McLeod, 2007). Further, adolescents perceived peers with schizophrenia as more violent (72%), more suicidal (76%), and less likely to be academically successful (70%; Penn et al., 2005). These attitudes extend to contact with treatment as over one-third of adolescents associated moderate-to-high levels of stigma with mental health service use (Chandra & Minkovitz, 2006). Finally, increased prior contact with people with mental illness—rather than decreasing stigma as it does among adults—instead led to intensified stigma among adolescents via greater perceptions of responsibility and dangerousness (Corrigan et al., 2005). Considering these findings together, mental illness labeling effects might be quite severe among adolescents due to negative societal conceptions and anticipated peer rejection.

Although the effects of a psychosis risk syndrome have yet to be specified, two recent studies demonstrate how diagnosis and treatment for common (i.e., disruptive behavior, affective, and post traumatic stress) disorders impacts adolescents’ self-concept (Moses, 2009a, 2009b). Although reporting relatively low levels of perceived public stigma, labeled adolescents did endorse key expectations of societal devaluation such as their peers “teasing/harassing” or “looking down on” youth receiving mental health treatment (Moses, 2009b). Further, approximately half of respondents experienced personal forms of rejection related to treatment such as feeling “disrespected” and others “hurting their feelings”. Although this sample has particular characteristics that limit generalizability to adolescents who are ‘high-risk’ for psychosis (i.e., atypical to ‘at-risk’ adolescents, the Moses sample was severely impaired, placed in multiple human service systems, and had significant proportions of individuals with disruptive disorders and PTSD), this study supports the applicability of
‘Modified Labeling Theory’ (Link et al., 1989) to this sample of adolescents. Adolescents with greater awareness of societal devaluation tended to report more self-stigma (i.e., feeling ashamed or different), which in turn was associated with greater concealment of psychiatric problems. Most critically, the stigma constructs of societal devaluation and self-stigma strongly accounted for psychological well-being (i.e., depression and lowered self-esteem). Additionally, approximately 20% of adolescents ‘self-labeled’ by identifying mental illness as a core aspect of themselves (e.g., describing “my” mental disorder or “having a chemical imbalance”; Moses, 2009a). Self-labelers’ scored higher on self-stigma and depression than others. Finally, adolescents who were younger when first entering treatment reported greater self-stigma, higher likelihood of ‘self-labeling’, and more secrecy after controlling for level of functional impairment, suggesting greater impact of labeling among adolescents with less well-formed identities (Moses, 2009a, 2009b).

4.2 Stigma of ‘At-Risk’ States

While some possible risks of discrimination faced by people identified as ‘at-risk’ for psychosis—and the counterbalancing potential harmful consequences of late detection and under-treatment—have been reflected upon elsewhere (Corcoran et al, 2005), we might look to other well-established ‘at-risk’ conditions (e.g., genetic susceptibility) to further model the nature and likelihood of any potential discrimination. Recent studies in a small but emerging literature have focused on genetic discrimination, when asymptomatic individuals or their relatives are treated unfairly due to actual or presumed genetic characteristics (Tanne, 2008). In contrast to suggestions that genetic discrimination is not commonplace (Greely, 2005), the few available estimates of genetic discrimination reported by asymptomatic but ‘at-risk’ individuals for somatic conditions such as neurodegenerative conditions (e.g., Huntington’s disease) and familial cancers (e.g., hereditary breast cancer) include 11% in Australia (Taylor, Treloar, Barlow-Stewart, Stranger, & Otolowski, 2008), 13% in the United Kingdom for insurance-related discrimination (Low, King, & Wilkie, 1998), with a figure of 40% reported in Canada (Bombard et al., 2009). Although rates vary due to sampling differences (i.e., recruitment method), country of study, types of disorders and forms of discrimination assessed, these studies suggest that discrimination for ‘at-risk’ states affects a significant portion of individuals.

Analysis of the specific domains of discrimination reveals further patterns. In one study of 951 asymptomatic adults requesting genetic testing of neurodegenerative disorders (e.g., Huntington’s disease) or familial cancers in Australia (Taylor et al., 2008), among those reporting genetic discrimination, incidents with life insurance were most common (42%), followed by negative treatment from family (22%), healthcare professionals (20%), in general social contexts (11%), and employers (5%). Another study of 233 asymptomatic adults ‘at-risk’ for Huntington’s disease in Canada found comparable patterns—genetic discrimination occurred most often in life and disability insurance (29%), familial (16%), and social settings (12%), with less frequent discrimination taking place in healthcare (9%), employment (7%) or the public-sector (4%; Bombard et al., 2009). Two U.S.-based, small-scale qualitative studies of asymptomatic individuals at-risk (Quaid et al., 2008) or after testing genetically positive for Huntington’s disease (Penziner et al., 2008) revealed similar concerns about confidentiality. The Penziner et al (2008) study also supported these quantitative patterns—although 90% of respondents initially had little concern about

1Other characteristics in this sample differing from typical ‘high-risk’ for psychosis adolescents include the patients reporting a very early age (i.e., 7 to 10 years old) of illness onset, and the subjects’ parents generally being of lower educational status.
2However, ‘non-labelers’ tend to have a later onset of illness and to be male, suggesting that ‘high-risk’ for psychosis individuals (whose illness onset is typically in later adolescence and who are predominantly male—Woods et al, 2009) may be less liable to ‘self-label’.

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employment discrimination and disclosed their status to employers, 83% did not disclose to insurers and 93% reported negative incidents with family members.

Although the psychosis risk syndrome differs in significant ways from being genetically ‘at-risk’ for a later-life condition (i.e., the psychosis risk syndrome is typically diagnosed at an earlier age, is established primarily based on symptoms already present rather than genetic markers, and conveys a lower risk than other highly penetrant diseases such as Huntington’s disease), to the extent that common experiences of discrimination are shared with such ‘at-risk’ states, we can tentatively offer the following. First, discrimination based on an ‘at-risk’ for psychosis state is quite possible, if not likely. Second, such discrimination might likely take place in insurance and family domains, the latter of which being particularly surprising and noteworthy. The potential threat of discrimination by insurance companies is especially salient given current debate to reform rules governing insurance coverage in the U.S. On the interpersonal level, familial stigma signals that genetic susceptibility to illness may become “part of a family’s identity and pattern of behavior” (p. 6; Bombard et al., 2009) whereby gene-positive individuals also experience profound changes in “self-image and identity within the family” (p. 324; Penziner et al., 2008; Kenen, Shapiro, Hantsoo, Friedman, & Coyne, 2007). If ‘at-risk’ for psychosis patients also face negative familial attitudes (e.g., nearly all relatives of such patients in one small study agreed that “Mental illness can lead someone to behave in ways that make other people laugh”, Wong et al., 2009, while some parents in another study articulated qualitative themes of their children undergoing a profound transformation in identity such as “He adopted a whole new identity”. Corcoran et al, 2003), this may set into motion a key stigma mechanism by initiating internalized stigma among labeled individuals.

5. Recommendations for Measurement and Future Directions

We have provided a focal conceptual integration of the stigma literature in an attempt to learn how potential stigma of a psychosis risk syndrome might affect individuals, and how this syndrome’s particular characteristics may shape any possible manifestation of stigma. We highlight key forms of ‘internalized stigma’, emotional reactions, and harmful coping mechanisms as a consequence of labeling processes that interfere with adolescent identity formation and forms of ‘structural’ and familial discrimination that may potentially occur as a result of an individual’s ‘at-risk’ status. Accurate conceptualization of these core domains is a prerequisite for valid measurement of any possible stigma that a psychosis risk syndrome might confer.

Psychometric scales have been developed to assess these stigma constructs and might be effectively adapted for use with individuals identified as ‘at-risk’ for psychosis. To assess awareness of societal stereotypes, Link et al (1989) developed a “Perceived Devaluation-Discrimination” Scale to assess a respondent’s perception of what most other people believe in terms of how people who had been treated for a serious mental illness may be devalued or discriminated against. To assess internalized stigma, Corrigan et al (2006) have designed a measure assessing similar processes of ‘stereotype awareness’ (e.g., “Most people in the community think that people with mental illness act unpredictably”) which then further extend to the components of ‘stereotype agreement’ (e.g., “I agree that people with mental illness act unpredictably”) and finally, ‘stereotype self-concurrence’ (e.g., “Because I have a mental illness, I act unpredictably”). For labeled individuals, measures to assess stigma-related feelings—such as feeling misunderstood, different, and ashamed—and behavioral coping orientations— including negative coping strategies such as secrecy and withdrawal, and positive coping responses such as educating and challenging others—have also been developed (Link et al, 2002). Lastly, examples of items assessing experienced discrimination in familial and structural domains (i.e., education, housing opportunities and
health insurance coverage) have been developed in Wahl’s (1989) comprehensive measure of consumers’ experience of stigma. In addition to directly tapping the stigma constructs of interest, these instruments all have established good reliability and validity (see Link et al., 2004; Yang, Link, & Phelan, 2008).

Finally, our ability to assess the ultimate impact of a psychosis risk syndrome is complicated by its current limited use in specialized clinical research programs that go to great lengths to reliably diagnose individuals and to protect them from stigma. For example, McGorry (2001) deliberately provided their treatment center a generic name (“Personal Assessment and Crisis Evaluation”) and located it in a non-psychiatric setting (a youth health service) precisely to minimize labeling effects. Further, information was specifically conveyed to decatastrophize psychotic disorders. Although stigma was not formally assessed, McGorry et al (2002) reported no effects of stigmatization via routine clinician inquiry of a preventive intervention consisting of risperidone and cognitive-behavioral therapy for individuals identified as ‘at-risk’ for psychosis. These carefully crafted conditions for curtailing stigma among individuals identified as at a ‘high-risk’ for psychosis may differ considerably from future common use by community clinicians in the event that this psychosis risk syndrome is included in DSM-V. This risk is further magnified among the ‘false positives’ who may not convert to a future psychotic disorder (Corcoran et al., 2005). Assessing any potential stigma among these academic treatment cohorts, although a critical first step, may lead us to underestimate the degree of stigmatization that might occur in ‘naturalistic’ community studies. Field trials prior to DSM-V should account for this possibility by adopting systematic measures of stigma that we have identified above—i.e., internalized stigma, negative emotional reactions, harmful behavioral coping strategies, and structural discrimination-- to accurately assess any potential harmful effects that this psychosis risk syndrome might confer among community samples.

Our focal application of the extensive stigma literature to a psychosis risk syndrome supports arguments that early identification and treatment of incipient psychotic symptoms promise to reduce overall stigma among those who will exhibit further symptoms and may well develop future psychosis. However, our aim as clinicians and researchers should not be confined to forestalling the development of psychotic symptoms but to also understand and intervene with any possible inadvertent stigmatizing effects brought on by labeling, regardless of whether or not individuals ‘convert’ to subsequent psychosis. Comprehensive theoretical, and measurement, tools certainly exist to address this issue. We have provided a starting point for conceptualization and assessment which we hope will form a foundation for further empirical work regarding this critically important ‘at-risk’ designation.

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