

The burden of awareness of psychometric risk for schizophrenia

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Abstract

Participants in studies of psychometric risk for schizophrenia are rarely informed of their risk status. Nondisclosure may be justifiable if the harmful effects of disclosure outweigh its benefits. We examined whether disclosure may adversely affect well-being and, if so, factors that predict the degree of adverse effect. Undergraduates ($n=114$) rated the anticipated impact—on felt distress, coping, optimism, helplessness, future lifestyle choices, and survival—of discovering they were at risk for schizophrenia and six other diseases. They also completed measures of potential predictors of this impact, including knowledge about schizophrenia, vicarious experience of schizophrenia, their potential to suffer stigmatization because of schizophrenia, and schizotypy. Participants judged schizophrenia risk more negatively than risk for heart disease, arthritis, depression, and diabetes, and less negatively than risk for cancer and Alzheimer's disease. Higher disorder-nonspecific impact, greater stigma, and lower psychometric risk for schizophrenia together provided the best linear prediction of schizophrenia-specific impact. Awareness of schizophrenia risk creates a significant adverse impact, the level of which may be greatest among those with lowest risk.

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1. Introduction

General population screening for features of psychometric risk for schizophrenia (also called *schizotypy*, *psychosis proneness*, or *subclinical psychosis*) is based on the premise that the presence of such features indicates the presence of a vulnerability for schizophrenia or nonaffective psychosis (Meehl, 1990; van Os et al., 2000). Longitudinal research shows that the rate of nonaffective psychosis is higher among those who exhibit features of schizotypy than among those who do

not (Chapman et al., 1994; Poulton et al., 2000). Despite or perhaps because of this link, screening often proceeds without research participants being informed of the nature of the construct researchers presume they are measuring. Rather, participants are invited to complete surveys of *feelings* or *attitudes* or some equally imprecise construct (Chapman et al., 1982; Venables et al., 1990; Korfine and Lenzenweger, 1995; van Os et al., 1999). Others have completed schizotypy measures embedded within scales that measure *personality* (Golden and Meehl, 1979; Linscott et al., 2006) or *anxiety* (Nielsen and Petersen, 1976), or that make no reference to any particular construct (Claridge and Broks, 1984; Chapman and Chapman, 1989; Raine, 1991; Rawlings and MacFarlane, 1994). Although widespread, this practice raises several ethical questions

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if one assumes the rationale for screening has some merit. The importance of these questions is, perhaps, proportional to the confidence placed in theories and evidence that attributes of schizotypy mark risk for schizophrenia (Meehl, 1990; Chapman et al., 1994; Claridge, 1997; Kwapil et al., 1997; van Os et al., 2000).

On one hand, failure to disclose interest in the underlying risk status may be perceived as paternalistic and contrary to the principle of informed consent (World Medical Association, 2004). Some may perceive nondisclosure as pre-empting enquiry from participants about their risk status and as subverting regulations and statutes governing health information and research participants' rights. On the other hand, nondisclosure may be justified on several grounds. (a) Specifying the theoretical or conceptual objectives of the screening may elicit biased or defensive responding. (b) Disclosure of risk status may engender unwarranted stress and stigmatization, which in itself may augment risk. (c) The predictive value of the screening measures may not have been soundly demonstrated. (d) Theoretically, few who exhibit psychometric risk go on to develop schizophrenia (Meehl, 1990). (e) Although the procedures may identify a risk cohort, the level of risk should not be presumed to be equivalent among all individuals in the cohort. (f) Research screening is, by its very nature, cursory and an insufficient basis for judgments about an individual's level of risk.

However, there is a dearth of relevant empirical evidence to inform discussion of disclosure versus nondisclosure in this context, and the ethics of general population screening for schizotypy has not been more widely debated. Yet evidence and debate on this issue is essential for meaningful progress in schizotypy research, particularly given the growing interest in the potential of screening methods to advance understanding and practice related to prodromal schizophrenia (Corcoran et al., 2005; Freedman et al., 2005). In the coming years, greater attention will undoubtedly be devoted to transitions to prodromal schizophrenia from precursor states such as schizotypy, and ostensibly well individuals who express endophenotypes or other attributes that mark risk (Corcoran et al., 2005), including general population samples of children (Cyhlarova and Claridge, 2005).

Therefore, our objective was to begin to examine just one of the many potential research questions that could inform such a debate: What is the impact on unsuspecting, non-help-seeking individuals of news they may carry risk for schizophrenia? It is conceivable that awareness of an elevated risk for schizophrenia, whether the risk is genuine or not, may itself become a significant source

of stress, altering psychological functioning and future help-seeking behaviour (Link et al., 1989). If so, it may become incumbent upon investigators to seek to mitigate these effects among those taking part in their research by targeting key factors that mediate this impact. Therefore, we also sought to identify variables that may affect the impact of such news. Studies of the perception of schizophrenia suggest that mediators may include stigma (Link et al., 1989; Angermeyer and Matschinger, 2003; Ertugrul and Ulug, 2004), knowledge about schizophrenia (Penn et al., 1999; Corrigan et al., 2001; Stuart and Arboleda-Flórez, 2001), and vicarious experience of psychosis (Kolodziej and Johnson, 1996; Corrigan et al., 2001). Greater psychometric risk for schizophrenia (schizotypy) may also predict greater impact because of the link between anxiety and schizotypy (Meehl, 1990; Braunstein-Bercovitz, 2000). Evidence that schizotypy predicts greater impact may suggest that those who are at risk are also those who would be most vulnerable to potential deleterious effects of awareness of risk. Finally, we also anticipated that the impact of awareness of risk for schizophrenia would be predicted by a more generalized tendency to react negatively to any unfavourable health news.

This question, on the burden of awareness of psychometric risk, must be addressed in an incremental fashion. The ideal method for addressing this question involves informing unsuspecting individuals—both those who are and are not at risk—that they are at increased risk for schizophrenia, and observing the psychological consequences of such (mis)information over time. However, it is difficult to justify an adverse and hazardous procedure such as this without first exploring the question using more benign paradigms, albeit paradigms that is not ideally suited to it. Therefore, we asked research participants to *anticipate* the impact of awareness of a personal risk for schizophrenia at the time of discovery, as well as risk for other physical and mental disorders.

2. Methods

2.1. Participants

Undergraduate students ($n=114$, 29% male, age $M=19.6$ years, $S.D.=1.7$) enrolled in an introductory psychology course volunteered to participate in return for extra credit. All but three participants (97.4%) were in their first year studying psychology. The majority of participants were Caucasian or European (80.7%), with smaller numbers of Asian (9.6%), New Zealand Maori (4.4%), and people of other ethnic groups (5.3%).

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