



Insight into illness in patients and caregivers during early psychosis: A pilot study

Benjamin K. Brent^{a,b,*}, Anthony J. Giuliano^{a,b}, Suzannah V. Zimmet^{a,b},
 Matcheri S. Keshavan^{a,b}, Larry J. Seidman^{a,b,c}

^a Department of Psychiatry, Beth Israel Deaconess Medical Center and Massachusetts Mental Health Center, MA, USA

^b Harvard Medical School, Boston, MA, USA

^c Department of Psychiatry, Massachusetts General Hospital, Boston, MA, USA

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ABSTRACT

Background: Impaired insight into illness is common during early psychosis and has been associated with treatment delays and poorer long-term outcomes. The relationship between patients' insight into illness and their caregivers' knowledge about psychosis is putatively associated with treatment outcome but there is limited research about this. This pilot study was designed to test the hypothesis that caregivers' levels of insight into illness is associated with patients' insight into illness in early psychosis and would be related to caregivers' levels of critical, rejecting attitudes toward patients.

Methods: Patients with schizophrenia or schizoaffective disorder within 5 years of psychosis onset ($n = 14$) and caregivers ($n = 14$) of the patients' choosing were studied. Insight into illness was assessed in patients using the Scale to assess Unawareness of Mental Disorder (SUMD). Caregiver insight into illness was assessed with a modified version of the SUMD with questions rephrased to probe caregivers' understanding of the patients' illness. Caregivers' critical attitudes toward patients were assessed with the Patient Rejection Scale (PRS).

Results: Significant correlations were found between patients' and caregivers' awareness of need for treatment ($r = .55, p = .02$), awareness of symptoms ($r = .48, p = .04$) and between caregivers' awareness of illness and critical attitudes toward patients ($r = .65, p = .01$).

Conclusions: These findings suggest that caregivers' emotional characteristics and levels of insight into illness may be related to insight into illness in patients. Implications for family psychoeducational approaches to impairments of insight into illness during early psychosis are discussed.

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1. Introduction

Impaired insight into illness is one of the most common symptoms of psychotic disorders (Sartorius et al., 1972). Recent studies of early psychosis (i.e., the first 5 years of illness) document that 70%–90% of individuals exhibit at least some degree of reduced insight into illness (Mutsatsa et al., 2006; Thompson et al., 2001), with moderate to severe levels of impairment occurring in 30%–50% (Keshavan et al., 2004; Thompson et al., 2001). Poor insight into illness often complicates the course of treatment in early psychosis. Research over the past two decades has found that impaired insight into illness is reliably related to longer duration of untreated psychosis (de Haan et al., 2002), medication nonadherence (Hill et al., 2010), greater symptom severity (Mintz et al., 2004), and poorer functional outcomes (Mohamed et al., 2009). Understanding the determinants of poor insight into illness may contribute to the development of treatment guidelines for managing the

risks associated with impaired insight into illness in the early course of psychotic disorders.

Most contemporary conceptualizations of insight into illness are multidimensional and define it as awareness of having a mental illness, awareness of the need for and effects of treatment with medication, awareness of the psychosocial consequences of having a mental disorder, and awareness and attributions regarding specific psychotic symptoms (Amador and Kronengold, 1998). Recent research has documented modest but significant relationships between levels of impaired insight into illness and cognitive deficits (Aleman et al., 2006; Keshavan et al., 2004) and less consistently with symptom severity (Mintz et al., 2003) among individuals with early and chronic psychotic disorders.

Although caregivers are increasingly recognized as playing an important role in the treatment of individuals with early psychosis, the relationship between caregivers' knowledge about psychosis and patients' insight into illness has not been studied. Caregivers are often the first to become aware of their loved one's illness (Judge et al., 2005). After the onset of psychosis, caregivers commonly play a critical role in supporting medication adherence, treatment engagement, and encouraging improved social functioning (Sin et al., 2005). Greater caregiver involvement during early psychosis has been linked to

* Corresponding author at: Beth Israel Deaconess Medical Center, Department of Psychiatry, Massachusetts Mental Health Center, 401 Park Drive, The Landmark Center-2 East, Boston, MA 02215, USA. Tel.: +1 617 998 5025; fax: +1 617 998 5007.

E-mail address: bbrent@bidmc.harvard.edu (B.K. Brent).

improved medication adherence and fewer days spent hospitalized (Penn et al., 2005), and less involvement has been associated with longer duration of untreated psychosis and increased risk of medication non-adherence (Rabinovitch, et al., 2009).

Research on 'expressed emotion' (EE) and family psychoeducation (FPE) lend additional support for the idea that greater caregiver understanding about psychosis may lead to increased patient insight into illness. Ample research has demonstrated a reliable relationship between high-EE in caregivers (primarily reflected in critical caregiver attitudes toward patients) and increased patient relapse rates (Bebbington and Kuipers, 1994; Brent and Giuliano, 2007). Early EE research found that a key characteristic of high-EE relatives was that they were commonly unaware that their affected family member was suffering from a mental illness (Vaughn and Leff, 1981). Conversely, it has been found that low-EE caregivers are not only less critical, but tend to make attributions that reflect an understanding of their relative's illness (e.g., 'he's doing the best he can, but his illness makes it hard for him to make decisions') (Brewin et al., 1991). Further, low-EE has been associated with greater treatment adherence and improved clinical course (Sellwood et al., 2003). Expressed emotion research linking caregivers' lack of knowledge about psychosis with high-EE and poorer patient outcomes has, in turn, provided an important evidence base for the development of family psychoeducation treatment interventions for schizophrenia. Numerous studies have now shown that improved caregiver understanding of psychosis during FPE is associated with reductions in relapse rates among patients with chronic schizophrenia (McFarlane et al., 2003). Although not directly tested, it has been posited that improvement in patient insight into illness as a consequence of increased caregiver knowledge about psychosis during FPE may partly mediate better clinical outcomes (McFarlane and Lukens, 1998). That is, greater caregiver insight into illness and less caregiver criticism may have a de-stigmatizing effect on patients' beliefs about mental illness and create a social environment that fosters improved patient insight into illness.

This pilot study of patient-caregiver dyads explored relationships among caregivers' insight into illness and emotional characteristics and levels of insight into illness and symptomatology among outpatients with early psychosis. Cognitive abilities potentially influencing the capacity for insight into illness (e.g., estimated verbal IQ, speed of processing) were also assessed in both caregivers and patients. For the purposes of this study, we defined 'caregiver insight into illness' as a construct comprising a caregiver's level of awareness regarding a patient having a mental illness, the effects of and needs for treatment in the patient, the psychosocial consequence of the patient's illness, and awareness and attributions of the patient's specific symptoms. We tested two hypotheses: 1) that caregivers' insight into illness would be associated with caregivers' levels of criticism toward patients; and 2) that the degree of caregiver insight into illness would be associated with levels of insight into illness in patients with early psychosis.

2. Methods

2.1. Subjects

Participants included 14 patient-caregiver dyads. Patients were recruited from the Massachusetts Mental Health Center Public Psychiatry Division of the Beth Israel Deaconess Medical Center (Boston, MA). The study was approved by the Human Research Committee at Beth Israel Deaconess Medical Center.

The majority of patients (86%) were receiving treatment in a specialized program for early psychosis at the Massachusetts Mental Health Center (Prevention and Recovery in Early Psychosis; PREP). Eligible patients were within 5 years of the onset of a first episode of psychosis, carried schizophrenia-spectrum diagnoses (schizophrenia or schizoaffective disorder), were ≥ 18 years of age, English-speaking, had no substance abuse or dependence in the last 3 months, and had no history of neurological illness or pervasive developmental disorder. No

patients were evaluated while in the acute phase of psychosis; they were a minimum of 2 weeks post discharge from hospitalization for acute psychosis.

Diagnoses were established on the basis of medical record review and the clinical evaluation of a senior psychiatrist, expert in psychiatric diagnosis (SVZ) in accord with *DSM-IV TR* (American Psychiatric Association, 2000) criteria for schizophrenia and schizoaffective disorder. Each patient selected a caregiver of his or her choosing with whom he or she had a minimum of 16 h of contact per week over the past month. This minimum frequency of patient contact was intended to insure that caregivers would have had sufficient opportunity to become familiar with patients' current beliefs about their illness, attitudes toward treatment, and level of symptoms.

2.2. Procedure

Written informed consent was obtained from all participants prior to enrollment. Neurocognitive and psychological assessments were administered by a licensed psychiatrist (BKB) trained to reliability on all measures under the supervision of a fully trained and licensed neuropsychologist (AJG).

2.3. Measures

Patients' insight into illness was assessed using the Scale to Assess Unawareness of Mental Disorder (SUMD; Amador and Strauss, 1990). The SUMD is a semi-structured interview that can be used to rate both current and past levels of insight into illness. For the purposes of this study, only current insight into illness (i.e., insight into illness in the past week) was rated. The SUMD assesses several dimensions of insight into illness: awareness of having a mental disorder; awareness of the effects of and need for treatment with medication; awareness of the psychosocial consequences of having a mental illness; and, awareness and attributions related to specific symptoms of serious mental disorder.

We assessed awareness and attributions across eight commonly occurring symptoms – three positive symptoms (hallucinations, delusions, and thought disorder), three negative symptoms (anhedonia, blunted affect, and avolition), and two general symptoms (inattention and poor social relationships). Scores for each item range from "1" (full awareness) to "5" (severe/complete unawareness). Scores of "2" or "3" reflect degrees of partial awareness, whereas a score of "4" indicates moderately severe unawareness. Symptom awareness was only assessed if the symptom was rated ≥ 3 on the Positive and Negative Symptom Scale for Schizophrenia (PANSS; Kay et al., 1987) (i.e., is present at the minimum psychotic threshold). One patient was rated less than 3 (or below minimum psychotic threshold) on all PANSS symptoms. Thus, the analysis of patients' and caregivers' awareness of symptoms is based on ratings in 13 dyads. Attributions were only assessed for symptoms of which patients had an awareness rating of ≥ 3 (i.e., at least partial symptom awareness). Correlations between patients' and caregivers' awareness of symptoms and attributions included only patient-caregiver dyads in which a symptom or attribution was rated. That is, dyads with symptom ratings of '0' (i.e., 'cannot be assessed/item not relevant') were excluded from correlation analyses. We excluded dyads from analysis in which no symptom was rated in order to avoid overestimating the strength of the putative association between caregivers' and patients' symptom level insight given the study's small sample size.

Caregiver insight into illness was assessed using a modified version of the SUMD in which questions were rephrased to probe caregiver insight into a patient's illness – e.g., 'do you think that your son needs to take medication'? Our caregiver version of the SUMD follows the model of Smith et al.'s (1997) adaptation of the SUMD to evaluate insight in significant others of patients with chronic schizophrenia. Caregivers' levels of the critical dimension of

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