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Is antipsychotic medication stigmatizing for people with mental illness?

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Abstract
Antipsychotic medications are clearly identified as important in the treatment of individuals with schizophrenia and with bipolar disorder. However, negative societal reaction related to having a serious mental illness and the socially undesirable side effects associated with antipsychotic medication treatment may combine to worsen stigma associated with treatment for mental illness. Specific stigmatizing effects of antipsychotic therapy may be difficult to evaluate independently from factors such as symptoms, insight into illness and side effects. Attitudes towards antipsychotic medication may be positive in individuals who recognize therapeutic drug effects, however other individuals may view medications negatively due to a sense of stigma. Stigma among individuals with bipolar disorder in relation to treatment with antipsychotic medication has not been well addressed in the literature. An additional concern among individuals with bipolar disorder who receive antipsychotic medications may be the notion that antipsychotics are 'schizophrenia drugs', and thus an inappropriate treatment for their condition. Antipsychotic medications can be stigmatizing for patients with serious mental illness, however the roots of stigma are extensive, and efforts to minimize stigma can only be successful when addressed by the individual with illness, their families and loved ones, treatment providers and society at large.

Antipsychotic medications and the treatment of serious mental illness

Antipsychotic medications are a cornerstone of treatment for individuals with serious mental illness, and have been widely utilized since the introduction of chlorpromazine five decades ago. For the treatment of patients with schizophrenia, the conventional antipsychotic agents as a class ushered in the era of modern psychopharmacology. Conventional antipsychotic medications are effective in reducing psychotic symptoms, but differ in their potency and side effect profiles. A major concern with conventional antipsychotic medications is their propensity to induce extrapyramidal symptoms and tardive dyskinesia (TD), a condition that is potentially debilitating and often creates social problems for affected individuals due to obvious, involuntary movements of the face, neck, trunk or extremities (Katschnig, 2000; Simpson, Pi, & Sramek, 1982). Individuals with severe TD may be ostracized because their appearance and psychosocial difficulties are common in individuals with severe forms of TD (Yassa, 1989).

Since the 1990s when clozapine and other novel or atypical antipsychotic drugs were introduced, the use of antipsychotic medications has become more complex. Compared to older agents, atypical antipsychotic agents have a reduced propensity to cause extrapyramidal symptoms, but may be associated with other side effects that create socially undesirable conditions such as weight gain and obesity (American Diabetes Association & American Psychiatric Association, 2004). A recent report comparing medication treatment outcomes among 1493 patients with schizophrenia (Lieberman et al., 2005), the US CATIE (Clinical Antipsychotic Trials of Intervention Effectiveness) study, suggested that over an 18-month period, approximately 74% of patients with schizophrenia discontinued antipsychotic medication. The majority of individuals prescribed antipsychotic drugs, which included both newer atypical agents as well as the conventional neuroleptic perphenazine, stopped assigned treatment owing to inefficacy, intolerable side effects or for other reasons (Lieberman et al., 2005). It is notable that nearly 30% of individuals in treatment in the CATIE study stopped medication on their own. Thus, while newer drugs may have differing side effect profiles compared to older agents, it appears as though acceptability of antipsychotic agents from a patient perspective is still quite limited.

Over the last decade, antipsychotic agents, particularly the newer, atypical antipsychotic compounds have been widely used to treat patients with bipolar disorder, and in fact there has been a convergence of treatment modalities for schizophrenia and for bipolar disorder

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(Citrome, Goldberg, & Stahl, 2005). Data from a large, US government healthcare database in 2003 suggested that 45% of individuals with bipolar disorder are prescribed antipsychotic medications, usually on a long-term basis (Sajatovic, Valenstein, Blow, Ganoczy, & Ignacio, 2006). Side effects with antipsychotic medication treatment among individuals with bipolar disorder may be substantial, and it has been reported that some side effects, such as weight gain, may be compounded when antipsychotic drugs are used concomitantly with traditional mood stabilizing medication such as lithium or anticonvulsant medications (Ghaemi, 2000). It has been demonstrated that approximately one in two individuals with bipolar disorder do not take antipsychotic medications as prescribed (Sajatovic et al., 2006).

Thus, antipsychotic compounds are widely prescribed to treat individuals with serious mental illness, including patients with schizophrenia, schizoaffective disorder and bipolar disorder. Unfortunately, in spite of substantial technological gains there appear to be significant obstacles to best outcomes including non-adherence with treatment.

Stigma and antipsychotic medications

While antipsychotic medications are clearly identified as treatments of choice in the management of both schizophrenia and of bipolar disorder (American Psychiatric Association, 2002; Gaebel, Weinmann, Sartorius, Rutz, & McIntyre, 2005) many individuals with these disorders, as noted above, do not take prescribed medications. It is likely that stigma related to having a serious mental illness and the socially undesirable side effects associated with antipsychotic medication treatment may combine to worsen stigma associated with treatment for mental illness, and in more extreme cases, may contribute to treatment non-adherence. Lee, Chiu, Tsang, Chui, and Kleinman (2006) recently evaluated the issue of stigma among Chinese patients with schizophrenia via use of focus groups and a questionnaire administered to 320 patients with schizophrenia and 160 patients with diabetes. Results suggested that patients with schizophrenia were more stigmatized than patients with diabetes, and that medication-induced stigma occurred in 48% of individuals with schizophrenia. Stigma led to unwelcome disclosure of illness, workplace difficulties, family rejection and treatment non-adherence. Hudson and colleagues (2004) analysed barriers to medication adherence among 153 patients with schizophrenia, and found that the most common patient-reported barriers included stigma of taking medications and of adverse drug reactions (forgetfulness and lack of social support were also noted to be significant barriers to medication adherence).

Numerous reports dealing with the individual and larger effects of stigma suggest that stigma is problematic on multiple levels, affecting not only the individual with serious mental illness, but also has negative effect on families and caregivers (Rudge & Morse, 2004; Struening et al., 2001; Tsang, Tam, Chan, & Cheung, 2003). Struening (2001) conducted a study of 461 caregivers of persons with serious mental illness to evaluate caregiver's perceptions of the extent of society's devaluation of consumers and their families. Most (70%) caregivers indicated a belief that patients with serious mental illness are devalued, and 43% expressed the belief that patient families are devalued as well (Struening et al., 2001). There was no difference in perception of devaluation between families of patients with schizophrenia vs. patients with bipolar disorder.

Subjective experience of taking antipsychotic medications among populations with serious mental illness

Subjective experience of illness refers to the psychocultural perception of illness lived by an individual. Subjective experience may vary in relation to ethnicity, age, gender, and socioeconomic status, and is a dynamic process that is likely to change over an individual's life time and circumstances. Subjective experience with respect to antipsychotic medications among individuals with serious mental illness appears to be highly variable (Carrick, Mitchell, Powell, & Lloyd, 2004; Davidhizar, 1985; Jenkins et al., 2005). Among some individuals, severe negative emotional/physical response in relation to conventional antipsychotic treatment – 'dysphoria' – may lead to non-adherence with treatment, poor outcomes or even suicidal behaviour (Awad, Voruganti, Keslegrave, & Hogan, 1996; Moore, Sellwood, & Stirling, 2000; Van Putten, May, Marder, & Wittmann, 1981). At the other end of the spectrum, individuals receiving antipsychotic medications may perceive a daily benefit from taking their medication (Jenkins et al., 2005; Loffler, Kilian, Toumi, & Angermeyer, 2003). Despite substantial side effects from medication such as weight gain, some individuals perceive an advantage to medication treatment with respect to reduced relapse rates and fewer hospitalizations (Jenkins et al., 2005). Other individuals may perceive both positive and negative aspects of antipsychotic medication treatments (Loffler et al., 2003), but may not always be able to readily articulate their varied components of subjective response to medication (Carrick et al., 2004).

Carrick and colleagues (2004) conducted a qualitative evaluation of subjective experience of side effects of antipsychotic medication using both in-depth interview analysed using grounded theory, and then a subsequent series of focus groups. Results indicated that individuals on antipsychotics did not see side effects and symptoms as separate issues, but described drugs as 'good' or 'terrible', an indication of the total impact of their treatment. Some patients with schizophrenia in the study by Carrick and colleagues (2004) expressed the notion that the 'medical establishment' wanted to keep people on medication, sometimes seen by patients as unsuitable or at higher levels than the patient wished.

Against this rather complicated contextual background where subjective experience is a combination of patient factors, the treatment relationship and the cultural/social setting, specific stigmatizing effects of antipsychotic therapy may be somewhat difficult to evaluate independently from factors such as symptoms, insight into illness, and side effects. Loffler and colleagues (2003) evaluated 307 schizophrenic patient's subjective reasons for compliance and non-compliance with neuroleptic treatment using a standardized rating scale, the Rating of Medication Influences (ROMI), developed by Weiden (1994). While approximately half of patients in the study by Loffler considered adverse effects to be a reason for medication non-adherence, the authors also noted 'Nearly every tenth patient was reluctant to take the medication because of embarrassment over the illness or the treatment, or because he or she was afraid to experience any kind of stigmatization because of the treatment' (Loffler et al., 2003). In the report by Loffler et al. (2003) embarrassment or stigma over medication or illness did not significantly differ between conventional oral neuroleptic medications, atypical antipsychotic medications, depot neuroleptics or combined neuroleptic medications. However, men were less likely to refuse drug treatment because of stigmatization compared to women ($OR = 0.353$, $p = 0.028$). Freudenreich and colleagues (2004) conducted a cross-sectional study of 81 outpatients with schizophrenia to evaluated clinical and demographic predictors of drug attitude, as measured by a standardized instrument, the Drug Attitude Inventory (Awad et al., 1993). Freudenreich and colleagues (2004) demonstrated that less awareness of current symptoms, presence of deficit symptoms and employment predicted a negative attitude towards medications, while extrapyramidal symptoms did not predict attitude and there was no difference between first- or second-generation antipsychotics. The authors concluded that while attitudes may be more positive in patients who recognize therapeutic drug effects, patients who work may view medications particularly negatively, possibly due to a sense of stigma (Freudenreich, Cather, Evins, Henderson, & Goff, 2004).

Populations with schizophrenia

Jenkins and colleagues (2005) recently conducted a study to evaluate subjective experience of treatment with antipsychotic medications. The project, funded by NIMH (MH-60232) was entitled the 'Subjective Experience and the Culture of Recovery with Atypical Antipsychotics (SEACORA)' study, and involved 90 community out-patient subjects with schizophrenia or schizo-affective disorder (according to SCID research diagnostic criteria). The research participants were studied in relation to their subjective experience of the atypical or second-generation antipsychotic medication they were taking (Table I). Data were derived primarily from semi-structured anthropological interviews (Subjective Experience of Medication Interview of SEMI) that inquired into everyday routines, medication and treatment, and the experience of stigma (Jenkins & Carpenter-Song, 2005).

Coding was completed by the authors (JHJ, ECS) having established coding definitions. Inter-rater reliability of coding at the most basic levels of analysis was completed by independent co-ratings of twenty randomly chosen cases that were tallied and analysed for kappa co-efficients of agreement

Table I. Sociodemographic and clinical characteristics seacora participants ($n = 90$).

Gender		
Male	49	54.4
Female	41	45.5
Ethnicity		
Euro-American	70	77.8
African American	20	22.2
Mean Age (SD)	40.7 (7.9)	
Diagnosis		
Schizophrenia	73	81.1
Schizo-affective	17	18.9
Mean age at onset (SD)	20.6 (7.3)	
Mean years ill (SD)	20.1 (8.4)	
Hospital Admissions		
Mean (SD)	7.0 (7.0)	
Current atypical antipsychotic		
Clozapine	51	56.7
Risperidone	16	17.8
Olanzapine	15	16.7
Other	8	8.9

Note: *Due to rounding, percent may not equal 100; Adapted from: Jenkins, J. H., Strauss, M. E., Carpente, E. A., Miller, D., Floersch, J., & Sajatovic, M. Subjective experience of recovery from schizophrenia-related disorders and atypical antipsychotics. *International Journal of Social Psychiatry*, *51*, 211–217.

by the project co-investigator (Milton Strauss) with substantial psychological research design and statistical expertise.

A subject's narrative experience was coded for the presence of stigma if at least one of the following conditions were met: (1) the subject conveyed that social response was negative with respect to how others respond to his/her illness; (2) the subject indicated they perceived stigma in relation to their illness; (3) the subject articulated that s/he does not tell others that s/he has a mental illness or that s/he takes medication. In situations where the subject expressed no attempt to conceal illness or medication from others, or in which the subject did not elaborate on stigma, the absence of stigma was coded. Coding a 'no' response cannot be considered an indication that the subject did not perceive or experience stigma but rather that the response reflects an absence of a narrative report of stigma in the interview transcript. Good inter-rater reliability (Kappa = 0.64) was obtained for the coding schema. One pair of raters independently coded 20 randomly selected responses. We found that the subjective experience of stigma was pervasive, occurring across an array of social settings, with 96% reporting awareness of stigma according to responses coded reliably in relation to operational criteria (Jenkins & Carpenter-Song, 2005). In addition, we identified nine primary contexts for the awareness of stigma and mental illness of which subjects were aware: (1) gender; (2) work; (3) social relations (family, friends, acquaintances); (4) dating; (5) medications; (6) self-presentation; (7) popular and media perceptions; (8) reproduction of stigma; and (9) social class and ethnicity (Jenkins & Carpenter-Song, 2005). An example of a Euro-American male who struggled with stigma attached to medication is taken from the following qualitative SEMI excerpt:

> I'll tell people I'm taking an antipsychotic, and they're like 'You don't need to take that.' They just give you that look, that shocked look, and then that jump a couple steps back. And I say, 'I know I have to take it, because I've been without it before'... And they start arguing with me, and I just leave and look back, because I know better.

Populations with bipolar disorder

Stigma among individuals with bipolar disorder has not been widely studied (Hayward, Wong, Bright, & Lam, 2002), and the specific point of subjective experience and of stigma in relation to treatment with antipsychotic medication has not been well addressed in the literature. Hayward and colleagues (2002) suggested that the issue of stigmatization is of considerable clinical significance among individuals with bipolar disorder, and appears to be relatively independent of mood state. A recent report by Sajatovic and Jenkins (2006) noted that stigma is widely experienced by patients with bipolar disorder, and does not appear to differ greatly among men or women or be experienced differently by individuals of different ages. Individuals with bipolar disorder may have had prior negative subjective experience with antipsychotic agents that may affect their future outlook on antipsychotic therapy, and which, when combined with the stigmatizing effects of medication treatment in general, may put these individuals at particularly high risk for non-adherence and poor outcome. Strejilevich and Garcia Bonetto (2003) identified the neuroleptic drug haloperidol as the compound to which the largest proportion of patients with bipolar disorder (86%) rated as their 'worst' treatment memory. In contrast, in the report by Strejilevich and Garcia Bonetto (2003), drugs related to 'best' treatment memories by patients with bipolar disorder were lithium and divalproex. It is not clear how newer antipsychotic drugs may be subjectively experienced by patients with bipolar disorder compared to older neuroleptic agents.

An additional concern among individuals with bipolar disorder who receive antipsychotic medications may be the notion that antipsychotics are 'schizophrenia drugs', and thus an inappropriate treatment for their condition. Highet and Colleagues (2004) conducted a qualitative analysis of treatment experience for individuals with bipolar disorder that included 49 people participating in focus groups or in-depth interviews. A major concern expressed by patients with bipolar disorder was delayed or inaccurate diagnosis of bipolar disorder, a situation that persisted for many years for some patients. Individuals were most often diagnosed incorrectly as having schizoaffective disorder, attention deficit hyperactivity disorder, unipolar depression and/or psychosis (Highet, McNair, Thompson, Davenport, & Hickie 2004). One might expect that unless the use of antipsychotic medication is clearly explained as an appropriate treatment for bipolar illness among individuals who have previously been incorrectly diagnosed, it is possible that use of antipsychotic drugs may be perceived as stigmatizing and consistent with an inaccurate diagnosis.

Minimizing stigma associated with antipsychotic therapy in patients with serious mental illness

It is clear that antipsychotic medications can be stigmatizing for patients with serious mental illness, however the roots of stigma are extensive, and efforts

to minimize stigma can only be successful when addressed by the individual with an illness, their families and loved ones, treatment providers and society at large. On an individual level, education regarding the biological constructs of illness, and involvement in self-help or peer support groups may be beneficial in combating the malignant effects of stigma on self-esteem. While membership in a stigmatized group is often assumed to have negative consequences (Camp, Finlay, & Lyons, 2002), individuals with serious mental illness may find ways of coping with stigma that are positive and constructive, thus delineating a clear difference between society's negative representations of the mentally ill and their own personal, 'no-fault' construction of illness. Camp and colleagues (2002) have noted that among women with chronic mental illness, personal rejection of critical and stigmatizing labels has a protective effect on self-esteem. Families and significant others also may benefit from education regarding illness and consumer organizations that may lessen family burden and stigmatization. It has been noted that distress to family members and caregivers is further compounded by lack of information, and exclusion from the treatment and management process (Highet et al., 2004). Providers can minimize the stigmatizing effects of antipsychotic medication by particular attentiveness to adverse effects that patients may be reluctant to admit cause social embarrassment or distress such as weight gain or sexual dysfunction. Treatment regimens that do not expose the mentally ill individual to possible negative attention such as having to take medication at work or school should be avoided if at all possible. Finally, the mental health community is obligated to address the issue of stigma in all its variations – not just with respect to having an illness, but all the effort and commitment that treatment and recovery entail.

Conclusion

Treatment with antipsychotic medications may contribute to stigma experienced by individuals with serious mental illnesses such as schizophrenia, schizoaffective disorder or bipolar disorder. While newer antipsychotic drugs may have fewer or different side effects compared to older neuroleptic agents, stigma may remain a substantial influence on medication adherence. In fact, on the basis of research in schizophrenia (Jenkins & Carpenter-Song, 2005; Jenkins et al., 2005; Lee, 2006; Stuening, 2001), and in bipolar disorder (Hayward et al., 2002; Sajatovic et al., 2006) it appears that stigma associated with antipsychotic medications is not only pernicious, but pervasive across an array of personal and social contexts. Efforts to minimize stigma must include patients, families, providers and society at large.

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