Adolescent Experience of Psychotropic Treatment

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Abstract Despite growing concern over the treatment of adolescents with psychiatric medications, little research has examined youth understandings and interpretations of mental illness and psychotropic treatment. This article reports the exploratory findings of semi-structured and open-ended interviews carried out with 20 adolescents diagnosed with one or more psychiatric disorders, and who were currently prescribed psychiatric medications. Grounded theory coding procedures were used to identify
themes related to adolescent subjective experience with psychiatric medications. The categories identified are interpreted as different points of view through which adolescents understand and take action upon their illness concerns; their need for medication treatment; their perceptions of how medications work; their responses to parental and other influences upon medication treatment; and, their everyday management activities.

Key words adolescent • medication management • psychiatric medication • qualitative research • subjective experience.

INTRODUCTION

Concern regarding adolescent mental health treatment with psychiatric medication has intensified among researchers, families, and practitioner groups, as the rate at which youth are prescribed psychotropic agents has increased over the last 20 years (Cooper et al., 2006; Olsson, Marcus, Weissman, & Jensen, 2002; Thomas, Conrad, Casler, & Goodman, 2006; Wong, Murray, Camilleri-Novak, & Stephens, 2004; Zito et al., 2003). Given this increasing use, researchers have called for studies of safety and efficacy because, it is argued, youths may respond to psychiatric medications differently than adults (Findling & Wiznitzer, 2003). Yet despite increasing scientific investigation into the effectiveness and tolerability of psychotropic agents in young people, there are limited data on how adolescents prescribed psychotropic agents subjectively experience medication treatment. We should not assume that youth have understood their illness, made sense of their medication treatment, and have adhered to a regimen as have adults. Indeed, social scientists have emphasized the many ways, active and passive, in which adults understand mental illness, diagnosis, medication treatment, and adherence (Charmaz, 1990; Conrad, 1985; Jenkins, 1994; Karp, 1996; Kleinman, 1988). Among adults with major depression, for example, David Karp (1996, p. 102) concluded that, ‘... the experience of taking antidepressant medications involves a complex and emotionally charged interpretive process in which nothing less than one’s view of self is at stake’. Understanding the interpretive or psychosocial aspect of youth psychotropic treatment, as Karp has argued for adults, may improve youth medication treatment. Thus, while the knowledge gap about the safety and efficacy of youth psychotropic treatment is gradually being addressed, we must now turn our attention to how youth make the treatment experience meaningful (Floersch, 2003).

Health research has demonstrated that adolescents draw upon personal perceptions, beliefs, and meanings in their experience of medical interventions. For example, adolescents modify medical advice about asthma when they believe that their knowledge of physical events supersedes the knowledge of doctors (Buston & Wood, 1999; Jessop & Rutter, 2003).
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Others report that adolescents discontinue asthma medication when they are unaware of specific bodily symptoms such as dyspnea (van Es et al., 1998). It has been shown that adolescents with chronic asthma stopped medication when they thought it was ineffective, or when believed they did not have the illness (Buston & Wood, 1999; van Es et al., 1998). Research on diabetic and asthma patients has found that adolescents may also assert autonomy by resisting standard treatment (Adams, Pill, & Jones, 1997; Kyngas & Hentinen, 1995) and may not adhere to prescribed treatments when they do not feel like taking medication (Hanna & Guthrie, 2000; van Es et al., 1998). Similarly, HIV-positive adolescents report how they avoid antiretroviral regimens when they feel healthy (Pugatch, Bennett, & Patterson, 2002). Cromer and Tarnowski (1989) show how adolescents treated for general medical conditions stop medications that prevent illness progression or episodic exacerbations when interventions lack the behavioral reinforcement of immediate relief from physical symptoms. In short, the literature on illness beliefs in medicine suggests that adolescents respond to medication treatment in profoundly personal ways that influence adherence and treatment effectiveness.

In this article, we report qualitative findings from a larger mixed-method study of adolescent psychotropic experience. Our aim here is to use grounded theory coding procedures to identify thematic categories adolescents use in making meaningful the psychotropic experience, specifically: (1) how do adolescents internally represent illness concerns and need for medication treatment?; (2) how do adolescents think medications work?; and, (3) how do adolescents perceive their participation in routine medication management activities?

Method

Sample

Subjects were recruited through discussions with professional staff, and fliers and posters aimed at patients seen within the outpatient clinic in the Division of Child and Adolescent Psychiatry at a university hospital, community mental health outpatient settings, and an alternative high school for adolescents with emotional and behavioral problems. Only adolescents, ages 12 to 17, meeting DSM-IV criteria for a psychiatric illness and currently being prescribed a psychotropic medication were eligible. Participants were excluded when parents reported that the adolescent had not taken psychotropic medication at least once in the past 30 days. Moreover, adolescents with developmental disability (i.e., IQ lower than 70), a pervasive developmental disorder, seizure disorder, or an organic brain disorder, were not enrolled.¹
Measures

Interviews for this study were carried out using the Teen Subjective Experience of Medication Interview (TeenSEMI), a semi-structured interview instrument, adapted from the adult version. The adult SEMI was designed to obtain narrative data about medication treatment from those diagnosed with schizophrenia (Jenkins, 1997; Jenkins et al., 2005). The TeenSEMI was produced by eliminating or modifying questions for adults (e.g., questions about work, marriage, and recovery) and developing age-relevant questions (e.g., questions about school, peer, and family interactions). The final interview schedule, approximately 150 questions, included 9 categories related to illness, treatment, and medication: (i) treatment, illness, and medication history; (ii) perceptions of medication; (iii) managing, monitoring, reporting of medication experience; (iv) parent and adolescent interaction regarding medication management; (v) illness and medication stigma; (vi) adolescent and school interactions regarding medication management; (vii) adolescent and peer interactions regarding medication management; (viii) access to mental health services regarding medication experience; and, (ix) ethnicity, gender, and religious influences regarding medication experience.

In addition to data produced with the semi-structured instrument, we collected adolescent and family demographics and psychiatric/medication treatment history. The Kiddie Schedule for Affective Disorders for School-Age Children Present and Lifetime Version (K-SADS-PL) (Kaufman et al., 1997) was used to determine participant diagnoses and the Child Global Assessment Scale (Shaffer et al., 1983) was used to assess overall functioning at home, with peers, and in school. The K-SADS-PL, a semi-structured research interview, has been used as a 'gold' standard to assign diagnostic categories in clinical drug trials or psychosocial intervention studies. It assesses symptom constellations according to DSM-IV psychiatric diagnoses in pediatric patients based on information provided by youth and parents or caregivers. The K-SADS-PL diagnostic interviews were conducted by a researcher (second author) trained as a 'rater' to administer the instrument. The use of the K-SADS-PL does not resolve the many issues related to diagnostic validity because symptom-based diagnostic systems are known to be culturally and historically sensitive (Horwitz & Wakefield, 2007; Kirk & Kutchins, 1992). For example, controversy exists over whether or not bipolar illnesses are accurately applied to youth (Moreno et al., 2007; Smith, 2007). In our research, the use of the K-SADS-PL meant that the researcher/rater followed the protocols for symptom-based diagnosis and when the outcome was bipolar, for example, trained raters (with a kappa ≥ 85) would have agreed with the diagnosis 85% of the time.
DATA ANALYSIS

In analyzing the data we assigned in-vivo code names using the actual words of the adolescent; the in-vivo codes were grouped by themes that emerged from comparing their shared characteristics. The specific grounded theory coding steps we utilized consisted of: (i) focused coding, which assigned in vivo codes that reflected data content; (ii) constant comparison of the focused codes, subsequently sorted by similar themes; and, (iii) axial coding, connecting the findings from steps one and two by sorting the discovered themes under broader umbrella categories and specifying how they relate to one another.3

This coding exercise resulted in sorting adolescent experience according to the following umbrella themes: (i) illness, disease, clinical symptoms, or clinical diagnosis; (ii) feelings or emotions; (iii) some aspect of the self; (iv) behavior; (v) relationships; (vi) cognition; (vii) physical concerns; (viii) expectations or hopes for what medications would do; and, (ix) medication management activities. In the final analytic step these themes were sorted according to the three research questions: illness and treatment perceptions about how medications work; and medication management perceptions.

Coding reliability was established by a process of seven coders independently coding 6 adolescent interviews; this combined effort generated nearly 500 in-vivo codes (themes based on concepts used by the interviewees). Then, the first author and study principal investigator (PI) examined the codes to eliminate redundancy. For example, when the same quotation was given different code names, they were reassigned to a single code. This process eliminated nearly 289 redundant codes, resulting in a ‘master codebook’ of 211 codes based on the first 6 interviews. This master codebook was then used by the coders for the remaining 14 interviews. Coders were instructed to create new codes from the 14 subsequent interviews only if codes in the master codebook failed to fit the new data; the PI then reviewed the code list generated from the 14 interviews and added new codes to the master list. The PI conducted a validity assessment of the final data set by checking that: (i) the codes referring to quotations were consistently applied across all 20 interviews; (ii) codes were appropriately grouped under the thematic categories; and, (iii) themes were appropriately grouped under the three research questions.

RESULTS

PARTICIPANT DEMOGRAPHICS AND CLINICAL PROFILE

Twenty youths participated in this study. The mean age was 14.75 years (SD 1.6); 9 were male and 11 female, 8 African American and 12
Euro-American; the mean years of education was 8.85 (SD 1.63). The mean number of prescribed psychotropic medications was 2.35 (SD 1.09) and average age at first prescription 10.35 years (SD 3.01; range 5–15 years). The mean number of prior hospitalizations was 3.4 (SD 2.3, range 0 to 9 times) and the age at first hospitalization 12.78 (SD 1.99).

There was a high rate of psychiatric comorbidity with subjects meeting diagnostic symptom criteria for an average of 2.35 (SD, 1.53) psychiatric diagnoses (see Table 1 for summary of psychiatric diagnoses).

The average CGAS (Clinical Global Assessment Scale) score at enrollment was 61.40 (SD 11.83), suggesting 'variable functioning with sporadic difficulties.' At the time of enrollment, parents (n = 20) reported adherence 'all the time' (n = 13), 'usually' (n = 6), and 'sometimes' (n = 1). Adolescents (n = 20) self-reported adherence 'all the time' (n = 18) and 'sometimes' (n = 2).

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**Illness and Medication Treatment Experience**

The TeenSEMI questions that elicited adolescent experiences of mental illness and treatment generated 74 in-vivo codes (linked to 273 quotations). These were compared and sorted to produce seven emergent themes: (i) emotion – references to emotional problems; (ii) diagnosis/disorder/symptom – reference to psychiatric illness, disease, or diagnosis; (iii) self – reference to some aspect of the self as the problem; (iv) cognition/thought – reference to cognitive problems; (v) intersubjective – reference to relationship problems; (vi) body – reference to physical problems, and; (vii) behavior/action – reference to behavioral or school problems. Column 1 of Table 2 gives examples of the themes and related adolescent responses.

**TABLE 1**

Diabetic profiles of subjects (N = 20)

<table>
<thead>
<tr>
<th>K-SADS-PL DSM-IV Diagnosis</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mood disorder</td>
<td>15</td>
<td>75</td>
</tr>
<tr>
<td>ADHD</td>
<td>12</td>
<td>60</td>
</tr>
<tr>
<td>Disruptive behavioral disorder</td>
<td>7</td>
<td>35</td>
</tr>
<tr>
<td>Substance abuse disorder</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Anxiety disorder</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Eating disorder</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Panic disorder</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Psychotic disorder</td>
<td>5</td>
<td>25</td>
</tr>
<tr>
<td>Other disorders</td>
<td>5</td>
<td>20</td>
</tr>
</tbody>
</table>

*Percentages sum to > 100 due to comorbidity
\textbf{Table 2}

Adolescent perceptions of medications – selected quotations

<table>
<thead>
<tr>
<th>Theme</th>
<th>Need for Medication Treatment</th>
<th>How Medications Work</th>
<th>Adherence to Medication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis/Disorder/Symptom</td>
<td>'it was for anxiety attacks and depression'</td>
<td>'They balance off my mood swings to where I won't have as many.'</td>
<td>[negative](^2) 'I don't want to get hooked on it or anything like that.'</td>
</tr>
<tr>
<td>Emotion</td>
<td>'I think it's mostly because I had a really, really bad attitude.'</td>
<td></td>
<td>[positive] 'At first my parents told me to, but once I see that that actually helps, I take it.'</td>
</tr>
<tr>
<td>Expectation/Hope</td>
<td>'... when I get angry, make me not like want to hurt my little sister cause she just gets on my nerves.'</td>
<td></td>
<td>[positive] 'It's my sleeping pill.'</td>
</tr>
<tr>
<td>Self</td>
<td>'I'm a mental case.'</td>
<td>'It's making me act better.'</td>
<td>[positive] 'Oh D, you can't behave? Oh D, you're bad. You're on medicine, cause kids in my school, they'll make fun of you.'</td>
</tr>
<tr>
<td>Behavior/Action</td>
<td>'... because I was having problems, real problems in school.'</td>
<td></td>
<td>[negative] 'I gain a relationship with my family again.'</td>
</tr>
<tr>
<td>Intersubjective</td>
<td>'... they thought that I was disrespecting them if I told them no.'</td>
<td></td>
<td>'I think it actually helps me to focus and I think that anger is more like in my own hands.'</td>
</tr>
<tr>
<td>Cognition/Thought</td>
<td>'... when I wasn't paying attention in school.'</td>
<td>'... listening and focusing and stuff.'</td>
<td>[positive] 'I don't want to take it trying to help something else and then it messes up another thing.'</td>
</tr>
<tr>
<td>Body</td>
<td>'... like headaches and stomachache.'</td>
<td>'It's supposed to like balance out something in your brain.'</td>
<td>[negative] 'That I'm going to get like five medicines at a time to take four times a day.'</td>
</tr>
</tbody>
</table>

\footnotesize{Notes:}
\(^1\) Assigned by sorting in-vivo codes and quotations into a common category.
\(^2\) Coders read adolescent responses or quotations and assigned them a positive or negative code based upon the adolescents' positive or negative attitude toward the medication. See examples in this table.
Some adolescents understood their need for help and the need for medication as ‘getting into trouble,’ as ‘swings in moods,’ as problems in ‘concentrating,’ and as problems ‘getting along with parents.’ Others, by saying, ‘I am ADD,’ or ‘I am bipolar,’ viewed their need for help as self-defining, while others externalized the diagnosis, saying, ‘I have an illness,’ or ‘I have depression,’ or ‘it applied to me.’

**How Medication Works**

Adolescent responses to queries about how medications work resulted in the creation of 87 in-vivo codes (linked to 441 quotations). These codes, representing how medications work, were contrasted and sorted, resulting in the identification of six themes: (i) body – how medication affected the body; (ii) emotion – how medication affected feelings and mood; (iii) cognition/thought – how medication affected thinking; (iv) behavior/action – how medication improved schoolwork or decreased aggression; (v) intersubjective – how medication improved relationships with mother, peers, and teachers; and, (vi) expectation/hope – what they wished medications would do for them. Column 2 of Table 2 offers examples of adolescent responses.

In general, adolescents reported that medication helped with sleep, ‘to act right,’ and ‘do stuff better,’ representing a belief that medication produced behavioral change. They described how parents and others influenced their experience and understanding of illness and medication; with this grouping of codes, we identified an intersubjective theme. For example, respondents (7 of 20) said that they learned from psychiatrists, mothers, television, internet, books, movies, and advertisements about how medications worked and what they affected. Among the intersubjective themes one was especially common (13 of 20): medications improved relationships at home, school, or with peers. Emotionally, medications were described as: ‘it stabilizes,’ ‘it levels me,’ ‘it evens my moods,’ ‘it calms me down,’ and ‘it makes me proud of myself.’ Adolescents hoped medications would do many things: provide a cure; control their anger. They hoped medications would not stop working, or that they would relieve family stress. They hoped for an easier regimen (e.g., a once a day drink, or patch instead of pills).

**Side Effects**

Adolescent experience with medication side effects was linked to 27 in-vivo codes. Comparison of the shared characteristics of the quotations linked to side effect codes produced two themes: (i) body – how treatment resulted in unwanted physical concerns and; (ii) emotion – how treatment resulted in unwanted feelings. Answers commonly associated with
physical/bodily themes were: sleepiness, stomachache/heartburn, headache, hand tremors, dizziness, reduced appetite, interference with taste, weight gain, and blurred vision. Other quotations were linked to codes that were grouped under an emotional theme: worries about being too happy or hyper, worries about becoming dependent on the medication, worries about feeling high, and worry that the medications made them 'act differently.' Only 3 of the 20 reported minimal or no side effects.

Perceptions of Adherence
Forty-eight in-vivo codes (linked to 180 quotations) referenced adherence experience; these were compared and grouped under seven themes: (i) expectation/hope – how medication had either disappointed or produced the desired effect; (ii) intersubjective – how relationships had improved; (iii) emotion – how feelings had improved or not; (iv) body – negative or positive physical concerns; (v) management – the tedious nature of daily management; (vi) cognition/thought – negative or positive; and, (vii) behavior/action – better grades and fewer behavioral problems (see Column 3 of Table 2 for examples). Although more adherence experiences were coded as negative (30 of 48 negative), positive feelings were frequently (18 of 48 positive) reported. Negative experience with medication was described as; bodily side effects, difficulties remembering to take medication and worries about dependency. Positive feeling, on the other hand, was linked to improvements in the quality of family, peer, and school relationships, emotional stability, and feeling that medication worked as hoped.

In summary, themes that emerged suggest that adolescents refer to their bodies, emotions, behavior, thoughts, self, and expectation/hope when making sense of medication treatment. It also appears that perceptions of medication are drawn heavily from parents and doctors; however, peers, siblings, counselors, Internet, television, and movies were also identified and could be significant interpersonal influences upon overall experience.

Case Illustration
Alicia, a 14-year-old Caucasian female in a regular eighth grade classroom (on an Individual Education Plan), was prescribed an antidepressant at age twelve and at the time of the interview was taking an antipsychotic and a mood stabilizer. The K-SADS diagnostic interview suggested a group of Bipolar I symptoms, euthymic, with rapid cycling. The diagnostic interview also suggested secondary diagnoses of ADHD-combined type, separation anxiety, oppositional defiant disorder, and conduct disorder. Alicia and her mother reported adherence to the medication regimen 'all of the time.' And her Clinical Global Assessment score was near the
mid-range, suggesting that at school, with peers and family, she had normal functioning with only occasional problems.

In response to TeenSEMI questions about the need for treatment (e.g., can you tell me in your own words, why you see the psychiatrist?), Alicia reported:

I think the reason why I'm going is because I have bipolar. I felt like I was doing fine, but I guess there were kind of different things going on. (coded Diagnosis/Disorder/Symptom)

I think it's mostly because I had a really, really bad attitude and if I didn't like what they [parents] said, I didn't want to hear it, and if I didn't like it and they kept telling me, I'd start screaming, so they knew something was wrong with me. (coded Emotion)

Because when I have a bad episode, I tend to black out, I don't remember things . . . like these glasses. I took them when I was mad and I twisted them all up and . . . I don't remember doing it at all. My mom just told me. (double coded, Body and Behavior)

Like I would have outbursts every single day. (coded Emotion)

[what do you think caused you to have these concerns?] I'm not sure if this is really it, but the move [referring to moving out of grandma's house after her death], because that just made my emotions go absolutely crazy. I mean I've lived in that house my whole life up to the 4th grade . . . That was my grandma's house before she died, I mean, and I met my best friend at that house, and it just kind of felt like, oh my god. Look I'm just totally leaving, and it just made me really upset and made my emotions go crazy. (coded Emotion)

Well that's when [six months after seeing a psychiatrist the first time] I first started to hear, they started saying bipolar, but also, I just remember two months into that, they had me ODD [oppositional defiant disorder], separation anxiety, and mania. (coded Diagnosis/Disorder/Symptom)

He [psychiatrist] kind of told my mom, before he told me, and then my mom sat down and explained it to me and we went and got some books from the library and we pretty much just read up on them and seen what they really were. (coded Intersubjective)

My best friend's twin brother . . . we became really good friends . . . we [her friend] would always make jokes about him and laugh at him because he was bipolar . . . and he kind of explained to me what it was and how you have to just deal with it. (coded Intersubjective)

At first I was like, 'no. I can't be bipolar.' That's just not me. I don't want to be it and then when I started actually seeing what was really going on, I'm just like, oh my god, I can't believe I just said that I wasn't this, and now I am. (doubled coded Diagnosis/Disorder/Symptom and Self)
I only thought it was people like really crazy, and you know like the hobo thing you see on the street singing to themselves and just walking back and forth, that's what I thought they were. Really all of it. Like I was able to relate to every single part of it. (coded Self)

I also still have separation anxiety. [and where did you get that name?] The CLINIC. I got that from The CLINIC, who told my mom, then my mom told me . . . She explained it to me . . . I didn’t realize like what separation anxiety is, and then she's just all like, 'well do you remember when grandma died?' And I go, ‘yeah.’ 'Do you remember how you won't let that go and you probably will never let that go?' I'm like 'Yeah . . . that is what separation anxiety is.' [and that again felt true to you?] yeah. (double coded, Self and Diagnosis/Disorder/Symptom)

In response to questions about how medications work, Alicia offered the following:

I started taking medicine and I would see a total different person when I took the medicine. I mean I wasn’t so angry and I was able to have a good time and laugh and just have fun. (triple coded Emotion, Self, and Intersubjective)

[what went through your mind when medication was first suggested?] I felt like they thought I was crazy. (coded Self)

[do you recall what that first medication was called?] Oh I can’t remember it. I know it’s always on TV with the little happy dot thing. [how did that feel to you when you saw something on TV that you were taking?] I just made fun of it a lot, like me and my mom. Like if I didn’t feel like taking it, my mom was like, ‘go take your happy dot pill.’ (coded Intersubjective)

[if a medication could do anything you wanted for the concerns you have mentioned, what would you wish it could do for you?] Nothing for me, mostly for my family. I feel that way so they won’t have to go through all the pain that they had to go through (coded Intersubjective)

[what do you think the (antipsychotic) actually does for you?] It’s my sleeping pill . . . I take it and I kind of get all goofy for like an hour, and then I’ll be really, really hungry and I’ll eat all these calories, then I’ll go to bed. [so you couldn’t sleep before the antipsychotic?] I could, just not as well. Like if I heard my dog walking pass my bedroom, I’d wake up and didn’t know what to do, and I’d lie there for like two hours trying to go back to sleep, because I can’t fall asleep without my TV on. So I’d turn on my TV and just lie there, watch TV and not be able to go back to sleep. [so the antipsychotic helps you sleep all through the night?] yeah. (coded Behavior)
[what do you think the (mood stabilizer) actually does for you?] It balances off all my . . . mood swings to where I won't have as many. It's like with my brother, he'll get me mad, and before [medication] I would just straight up and hit him . . . I don't get as aggravated . . . I mean when I was off the medicine, I would just kind of get into trouble for aggression. I got in a fight at school. I got suspended. I got put in the court system. I beat another girl up outside of school. (coded Behavior and Emotion)

[what are some things that medication can't do for you?] Right now I'm loving life. I have great friends. I mean there's nothing better that I can ask for right now. It can't just totally keep me happy all the time. It's just the part that everybody has . . . it is normal to get a little annoyed . . . I mean it [medication] controls it [aggression] but it does not take all of it away.' (coded Emotion and Intersubjective)

[what do you think your mother or father want medication to do for you?] Right now my mom likes the medication on me. I mean she even said she couldn't ask for anything better . . . My dad, honestly, doesn't want me on medication, because when he was younger, he was on medication. It didn't work for him. But my mom said that it works, and he said that he's starting to know a difference, but he's still kind of like, 'well I still don't want her on medication.' (coded Intersubjective)

[how long do you think others believe you should take your current medication?] I don't want to take them at all, but it's something I have to do . . . the rest of my life . . . They told me I'm going to be bipolar for the rest of my life and I'm going to be stuck on medication. [who is they?] My mom, dad, my doctor, my psychiatrist, my counselor, my teachers, my [school] principal. (coded Intersubjective)

[some people believe that we should not take medication and fix ourselves, what do you think about that?] I thought the same way. I mean it's kind of like I was getting brainwashed by one of my friends, and she was like, 'by 2010 almost everybody in the world's going to be on medicine,' and then I started to see the real truth, and it's just I feel like why would they put me on it if it really didn't work? I mean are they trying to fool me or get my insurance money or something? But then I really found out. (coded Intersubjective)

How are we to understand the clinical/diagnostic and psychosocial referents in Alicia's narrative? First, while she was 'given' diagnoses for bipolar and separation anxiety, clinicians turned to her mother to offer explanatory accounts: 'He [psychiatrist] kind of told my mom, before he told me, and then my mom sat down and explained it to me.' And while Alicia internalized an illness/disorder identity – I am bipolar ('now I am') – she also produced a distance between herself and the diagnosis by stating that the diagnosis ('it') had been given to her ('they started saying'; 'they had me'). Moreover, while bipolar was something she had 'for life',

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assigned to her by clinics and psychiatrists, she also saw a possible connection to the death of her grandmother and the move from her grandmother’s house. She said, ‘it just made my emotions go absolutely crazy.’ And while she thought medication worked on her aggression, it seemed also to leave some part of it unaddressed.

Alicia wondered whether her friend was correct to think that by 2010 everybody in the world would be on medication? She seemed to be saying: ‘if everybody is on medication, and I am on medication, then I am like everyone.’ This was, however, more than a simple normalization of experience. It is in this complex, intersubjective dynamic that Alicia joined others to co-produce the meaning of the medication experience. Indeed, this intersubjective dynamic is to be found in all 20 interviews. The clinical implications, we believe, are far-reaching. Psychiatrists, for example, must attend not only to prescribing the antidepressant, they must grasp how Alicia, and her mother make sense of the ‘happy dot pill.’ The television advertisement referred to in the narrative above suggests that medication targets neurotransmitters and depressive/behavioral symptoms; but mother and daughter are equally influenced by the drug’s implied power to create happiness. Alicia and mother found humor in the commercial by joking about the tedious nature of daily medication management. Of the intersubjective influences on medication experience perhaps most significant was Alicia’s belief that taking medication both pleased her mother and resulted in fewer fights with her brother. Alicia’s motivation to adhere to the medication was related in part to her perception that it helped make peace in the family. This finding suggests that medicating adolescents is symbolically medicating a family because the effects of medication generate meanings that implicate an entire family system (Chubinsky & Rappaport, 2006; Oldani, 2009; Rappaport & Chubinsky, 2000).

**Discussion**

Alicia’s medication experience presents several possibilities for further inquiry. Peter Conrad (2007), for example, has recently looked at how social and psychological problems are increasingly framed by and acted upon through biomedical assumptions. Drawing on such work, one might explore the relationship between medicalization and psychiatric medications by examining how Alicia simultaneously adopts and accepts both the bipolar diagnosis and psychosocial explanations of her difficulties. For example, we might ask how psychiatric medicalization produces fundamentally new possibilities for conceptions of self, as determined by the medication experience. Moreover, asking such questions can highlight the analytical limitations of concepts such as medicalization and the globalization of pharmaceuticals. Thus while one can easily join Alicia in
imagining a world in which everyone is on psychiatric medications, globalization, like medicalization, is a not a sufficiently rich concept to provide an adequate account of how individuals ultimately make sense of their medication experiences. These concepts, for example, would not help us conceptualize how for Alicia the ubiquity of medication becomes a potential defensive projection aimed at normalizing stigma or shame about her illness or medication experience. David Karp shows in his work with teenagers how anti-depressants in schools produced an intersubjective experience of stigma (Karp, 2006). Whichever direction the cause and effect might run in these instances, there is little doubt that for Alicia the hoped-for symptom-focused biomedical model is just one of many ways in which she makes meaning of psychiatric medications.

Over the set of 20 adolescent respondents, personal and interpersonal themes of adolescent psychotropic treatment might be understood as different points of view through which adolescents understand and take action related to: their illness concerns; their need for medication treatment; their perceptions of how medications work; their responses to parental and other influences upon medication treatment; and their everyday management activities. The theme of expectation and hope seems particularly central to their experience. It is in the space between the successful and disappointing medication treatment that adolescents wonder: ‘why take medications,’ ‘what will they do for me,’ ‘will they harm me,’ and ‘how will I manage them.’ Our findings suggest that adolescents will deploy one or several personal and interpersonal life domain dimensions to answer these questions and in doing so make psychotropic treatment meaningful.

As is the case with all of those interviewed for this study, Alicia’s particular diagnosis and medication experience is mediated by complex social dynamics. Observation and interpretation of adolescent medication effects are shaped by family, community, cultural, and personal belief and attitude toward: the diagnosed illness; how diagnoses are made; and the treatment, including the nature of the relationship between practitioner and treatment recipient. Our model for representing adolescent medication experience and management is summarized in Figure 1. The model is comprised of five elements of a medication experience, represented vertically (highlighted in gray) as the socio-cultural dimension: (i) problem, (ii) prescription assessment, (iii) access and payment, (iv) monitoring and interpreting effects, and (v) reporting effects. Furthermore, pharmaceutical interests, insurance/payment policies, and the organization of local mental health services set the parameters for the medication experience. For example, the local service provider may be resource depleted or influenced by a single or reductionist model of the relationship between mind and body. Horizontally we have depicted the
Figure 1 Socio-cultural, personal, and interpersonal matrix of adolescent medication experience and management.
subjective (i.e., personal) and intersubjective (i.e., interpersonal) dimensions of the adolescent psychopharmaceutical experience.

The subjective aspect of medication treatment has two dimensions and addresses the degree and nature of involvement, passive or active (Longhofer, Floersch, & Jenkins, 2003b), in making sense of the biopsychosocial domains; Alicia, for example, was actively engaged in making a psychosocial claim about her illness: she wondered about the effect of her grandmother’s death on her intense affect. And while one might see this as active resistance to the biological diagnosis, Alicia just as actively embraced her bipolar diagnosis: she engaged with her mother to determine the cause of her affective storms. Moreover, she reported that medication reduced aggression and also linked the medication’s effect to an acceptance of the correct diagnosis, ‘. . . it balances off all my . . . mood swings to where I won’t have as many.’ Alicia’s references to the biopsychosocial domains of emotion, cognition, and body show us the personal and interpersonal dynamic of her medication experience and the sociocultural milieu organizing her experiences around DSM-IV categories and medication treatment. The aggregate data and case illustration remind us of the danger of reducing our assessment of medication treatment to its biological or clinical effects; assessment must include attention to extra-clinical, sociocultural effects.

The intersubjective dimension also refers to how passively or actively the adolescent engages others, (i.e., parents, peers, teachers, clinicians, and friends) the Internet, popular magazines or culture, and libraries in gathering information that shape how they make sense of the psychotropic experience. Alicia, for example, was influenced by the Zoloft commercial, as well as by a peer’s brother who had been diagnosed with bipolar disorder. She also took medication, in part, to please her mother. At the same time, her father remained skeptical of the pharmacological treatment. Indeed many adolescents in this study reported that fathers were not engaged in treatment decisions, and were similarly ambivalent. The influence of skeptical fathers on their children presents a challenge: when parents disagree over medication use, how does this affect the medication experience?

The system of medical, clinical diagnosis produces a particular intersubjective field for making meaning of everyday medication experience. And while it might be easy for some to imagine that psychiatric diagnoses are made based solely on ‘detecting signs that point to objective, measurable parameters’ (Verhaeghe, 2004, pp. 17–18) in practice psychodiagnostics always requires interpretation. Although at the time of Alicia’s interview bipolar disorder was the principal diagnosis, she had been given several diagnoses over the years. Clinicians prescribing medications are obligated to connect the suggested use and type of drug
(e.g., anti-psychotic, mood stabilizer, psychostimulant, etc.) to particular diagnoses. Yet, these data suggest that it does not necessarily follow that the recipient accepts the diagnosis and the connection between a specific disease/disorder and its associated medication. Diagnosing youth, moreover, presents serious challenges. Alicia’s history of multiple diagnoses illustrates this challenge and raises the question: which diagnosis did she identify with and why?

Table 3 compares the self-reported diagnosis of the 20 participants with that of the K-SADS-PL. The comparison shows that 13 of 20 adolescents did not report a disjuncture between their diagnostic understanding and the K-SADS-PL, a standard symptom-based assessment. For 7 (highlighted in gray), however, there was a disjuncture, raising questions about how they experienced the gap between the clinician’s diagnostic interpretations and their own understandings of the problem and associated medication treatment.

**Conclusion**

For most people who take aspirin for headaches, the hoped-for effect is credited to the power of the drug. Between the expected (hoped-for or desired) and the experienced effects of medication, there exists a phenomenological, subjective and intersubjective gap (Longoher & Floersch, 2004; Longhofer, Floersch, & Jenkins, 2003a). When medicine is believed to be the agent that delivers the expected effect, the gap between desired and experienced effects is narrowed. In such cases, patients are likely to interpret treatment effects as tangible and focused. On the other hand, this gap between expectations and experience may be quite large when the anticipated effects of a medication are less well defined and when others assert their expectations (Floersch, 2002). Thus, in relation to reducing or eliminating psychiatric symptoms like depression, anxiety, and irritability, the expected effects may be elusive, transient, or difficult to pinpoint. In the present study, Alicia, for example, regarded the medication’s role in reducing aggression in positive terms; yet she also recognized, ‘it doesn’t take it all away.’ She seemed to be asking: how much aggression is normal? Or: how much is left over after the medication takes care of its portion? There was another gap between her expectation that the medication will help her and that it would help others: ‘Nothing for me, mostly for my family.’ This gap represents a subjective and intersubjective space within which the medication recipient (or others in their network) observes, monitors, and interprets. Meanwhile, adolescents’ interpretations of medication effects are always embedded in the broader context of sociocultural factors related to mental health services and biopsychiatry.
<table>
<thead>
<tr>
<th></th>
<th>Self-Report Diagnosis</th>
<th>Primary KSADS-PL Diagnosis</th>
<th>Second KSADS-PL Diagnosis</th>
<th>Third KSADS-PL Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>N = 20</td>
<td>Bipolar</td>
<td>Bipolar</td>
<td>ADHD</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Seizures, does not know</td>
<td>Schizophrenia</td>
<td>Separation Anxiety</td>
<td></td>
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<td>2</td>
<td>Bipolar</td>
<td>Bipolar</td>
<td>ADHD</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>ADD</td>
<td>Bipolar</td>
<td>Conduct Disorder</td>
<td>ODD</td>
</tr>
<tr>
<td>4</td>
<td>Bipolar, ODD, Anxiety</td>
<td>Major Depressive Disorder</td>
<td>PTSD</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Depression</td>
<td>Major Depressive Disorder</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Bipolar, ADD, Depression</td>
<td>Bipolar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>ADHD, ODD</td>
<td>Bipolar</td>
<td>ADHD</td>
<td>ODD</td>
</tr>
<tr>
<td>8</td>
<td>Depression, Bipolar</td>
<td>Major Depressive Disorder</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Bipolar</td>
<td>Bipolar</td>
<td>ADHD</td>
<td>Panic Disorder</td>
</tr>
<tr>
<td>10</td>
<td>ADHD, Depression</td>
<td>Major Depressive Disorder</td>
<td>ADHD</td>
<td></td>
</tr>
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<td>11</td>
<td>Mood Disorder</td>
<td>Bipolar</td>
<td>Eating Disorder</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Depression, Eating Disorder</td>
<td>Bipolar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Bipolar, ADHD, Anxiety</td>
<td>Substance Induced Mood Disorder</td>
<td>ADHD</td>
<td>ODD</td>
</tr>
<tr>
<td>14</td>
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<td>Bipolar</td>
<td>ADHD</td>
<td>Enuresis</td>
</tr>
<tr>
<td>15</td>
<td>Forgot – does not know</td>
<td>Eating Disorder</td>
<td>Avoidant D/O</td>
<td>Enuresis</td>
</tr>
<tr>
<td>16</td>
<td>ADD</td>
<td>Bipolar</td>
<td>ADHD</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Did not give a name</td>
<td>ADHD</td>
<td>Enuresis</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Depression, ADD</td>
<td>Bipolar</td>
<td>ADHD</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>ADD</td>
<td>ADHD</td>
<td>Enuresis</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
ACKNOWLEDGEMENTS

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NOTES

1. This outpatient research protocol was reviewed and approved by the University of Hospitals Case Medical Center Institutional Review Board for Human Investigation. The parents/guardians of the research participants provided written informed consent and all adolescents provided written informed assent prior to study participation. The interviews conducted under the auspices of this study took approximately six hours. Parents received $50 and adolescents $65, respectively as honoraria.

2. Prior to administering the diagnostic assessment, the rater met adequate inter-rater reliability standards (kappa > .85) on five consecutive interviews while observing a trainer-rater and on five consecutive interviews while leading the interview; a rater’s kappa of ≥ 85 indicates that eighty-five out of hundred conclusions would reliably match other raters trained with the same protocol.

3. The type of coding procedure used in this analysis is a synthesis of the following grounded theory approaches: Boeije, 2002; Charmaz, 1990, 2006; Glaser & Strauss, 1967; Muhr, 1993; Sivesind, 1999.

4. Indirect support for these findings includes research that has emphasized that adult experience is mediated by culture, mental health systems, and medicalization processes (Conrad, 2007; Floersch, 2002; Jenkins et al., 2005; Karp, 2006; Kirmayer, Young, & Robbins, 1994; Kleinman 1988).

5. Results from one clinical drug trial have noted that a medication’s intended effect was moderated by the degree of family conflict (see Townsend, Demeter, Youngstrom, Drotar, & Findling, 2007).

REFERENCES


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Adolescent Experience of Psychotropic Treatment

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Abstract  Despite growing concern over the treatment of adolescents with psychiatric medications, little research has examined youth understandings and interpretations of mental illness and psychotropic treatment. This article reports the exploratory findings of semi-structured and open-ended interviews carried out with 20 adolescents diagnosed with one or more psychiatric disorders, and who were currently prescribed psychiatric medications. Grounded theory coding procedures were used to identify
themes related to adolescent subjective experience with psychiatric medications. The categories identified are interpreted as different points of view through which adolescents understand and take action upon their illness concerns; their need for medication treatment; their perceptions of how medications work; their responses to parental and other influences upon medication treatment; and, their everyday management activities.

**Key words** adolescent ∙ medication management ∙ psychiatric medication ∙ qualitative research ∙ subjective experience,

**Introduction**

Concern regarding adolescent mental health treatment with psychiatric medication has intensified among researchers, families, and practitioner groups, as the rate at which youth are prescribed psychotropic agents has increased over the last 20 years (Cooper et al., 2006; Olsson, Marcus, Weissman, & Jensen, 2002; Thomas, Conrad, Casler, & Goodman, 2006; Wong, Murray, Camilleri-Novak, & Stephens, 2004; Zito et al., 2003). Given this increasing use, researchers have called for studies of safety and efficacy because, it is argued, youths may respond to psychiatric medications differently than adults (Findling & Wiznitzer, 2003). Yet despite increasing scientific investigation into the effectiveness and tolerability of psychotropic agents in young people, there are limited data on how adolescents prescribed psychotropic agents subjectively experience medication treatment. We should not assume that youth have understood their illness, made sense of their medication treatment, and have adhered to a regimen as have adults. Indeed, social scientists have emphasized the many ways, active and passive, in which adults understand mental illness, diagnosis, medication treatment, and adherence (Charmaz, 1990; Conrad, 1985; Jenkins, 1994; Karp, 1996; Kleinman, 1988). Among adults with major depression, for example, David Karp (1996, p. 102) concluded that, '...the experience of taking antidepressant medications involves a complex and emotionally charged interpretive process in which nothing less than one's view of self is at stake'. Understanding the interpretive or psychosocial aspect of youth psychotropic treatment, as Karp has argued for adults, may improve youth medication treatment. Thus, while the knowledge gap about the safety and efficacy of youth psychotropic treatment is gradually being addressed, we must now turn our attention to how youth make the treatment experience meaningful (Floersch, 2003).

Health research has demonstrated that adolescents draw upon personal perceptions, beliefs, and meanings in their experience of medical interventions. For example, adolescents modify medical advice about asthma when they believe that their knowledge of physical events supersedes the knowledge of doctors (Buston & Wood, 1999; Jessop & Rutter, 2003).
Others report that adolescents discontinue asthma medication when they are unaware of specific bodily symptoms such as dyspnea (van Es et al., 1998). It has been shown that adolescents with chronic asthma stopped medication when they thought it was ineffective, or when believed they did not have the illness (Buston & Wood, 1999; van Es et al., 1998). Research on diabetic and asthma patients has found that adolescents may also assert autonomy by resisting standard treatment (Adams, Pill, & Jones, 1997; Kyngas & Hentinen, 1995) and may not adhere to prescribed treatments when they do not feel like taking medication (Hanna & Guthrie, 2000; van Es et al., 1998). Similarly, HIV-positive adolescents report how they avoid antiretroviral regimens when they feel healthy (Pugatch, Bennett, & Patterson, 2002). Cromer and Tarnowski (1989) show how adolescents treated for general medical conditions stop medications that prevent illness progression or episodic exacerbations when interventions lack the behavioral reinforcement of immediate relief from physical symptoms. In short, the literature on illness beliefs in medicine suggests that adolescents respond to medication treatment in profoundly personal ways that influence adherence and treatment effectiveness.

In this article, we report qualitative findings from a larger mixed-method study of adolescent psychotropic experience. Our aim here is to use grounded theory coding procedures to identify thematic categories adolescents use in making meaningful the psychotropic experience, specifically: (1) how do adolescents internally represent illness concerns and need for medication treatment?; (2) how do adolescents think medications work?; and, (3) how do adolescents perceive their participation in routine medication management activities?

**Method**

**Sample**

Subjects were recruited through discussions with professional staff, and fliers and posters aimed at patients seen within the outpatient clinic in the Division of Child and Adolescent Psychiatry at a university hospital, community mental health outpatient settings, and an alternative high school for adolescents with emotional and behavioral problems. Only adolescents, ages 12 to 17, meeting DSM-IV criteria for a psychiatric illness and currently being prescribed a psychotropic medication were eligible. Participants were excluded when parents reported that the adolescent had not taken psychotropic medication at least once in the past 30 days. Moreover, adolescents with developmental disability (i.e., IQ lower than 70), a pervasive developmental disorder, seizure disorder, or an organic brain disorder, were not enrolled.
Measures

Interviews for this study were carried out using the Teen Subjective Experience of Medication Interview (TeenSEMI), a semi-structured interview instrument, adapted from the adult version. The adult SEMI was designed to obtain narrative data about medication treatment from those diagnosed with schizophrenia (Jenkins, 1997; Jenkins et al., 2005). The TeenSEMI was produced by eliminating or modifying questions for adults (e.g., questions about work, marriage, and recovery) and developing age-relevant questions (e.g., questions about school, peer, and family interactions). The final interview schedule, approximately 150 questions, included 9 categories related to illness, treatment, and medication: (i) treatment, illness, and medication history; (ii) perceptions of medication; (iii) managing, monitoring, reporting of medication experience; (iv) parent and adolescent interaction regarding medication management; (v) illness and medication stigma; (vi) adolescent and school interactions regarding medication management; (vii) adolescent and peer interactions regarding medication management; (viii) access to mental health services regarding medication experience; and, (ix) ethnicity, gender, and religious influences regarding medication experience.

In addition to data produced with the semi-structured instrument, we collected adolescent and family demographics and psychiatric/medication treatment history. The Kiddie Schedule for Affective Disorders for School-Age Children Present and Lifetime Version (K-SADS-PL) (Kaufman et al., 1997) was used to determine participant diagnoses and the Child Global Assessment Scale (Shaffer et al., 1983) was used to assess overall functioning at home, with peers, and in school. The K-SADS-PL, a semi-structured research interview, has been used as a ‘gold’ standard to assign diagnostic categories in clinical drug trials or psychosocial intervention studies. It assesses symptom constellations according to DSM-IV psychiatric diagnoses in pediatric patients based on information provided by youth and parents or caregivers. The K-SADS-PL diagnostic interviews were conducted by a researcher (second author) trained as a ‘rater’ to administer the instrument.² The use of the K-SADS-PL does not resolve the many issues related to diagnostic validity because symptom-based diagnostic systems are known to be culturally and historically sensitive (Horwitz & Wakefield, 2007; Kirk & Kutchins, 1992). For example, controversy exists over whether or not bipolar illnesses are accurately applied to youth (Moreno et al., 2007; Smith, 2007). In our research, the use of the K-SADS-PL meant that the researcher/rater followed the protocols for symptom-based diagnosis and when the outcome was bipolar, for example, trained raters (with a kappa ≥ 85) would have agreed with the diagnosis 85% of the time.
DATA ANALYSIS

In analyzing the data we assigned in-vivo code names using *the actual words of the adolescent*; the in-vivo codes were grouped by themes that emerged from comparing their shared characteristics. The specific grounded theory coding steps we utilized consisted of: (i) focused coding, which assigned in vivo codes that reflected data content; (ii) constant comparison of the focused codes, subsequently sorted by similar themes; and, (iii) axial coding, connecting the findings from steps one and two by sorting the discovered themes under broader umbrella categories and specifying how they relate to one another.\(^3\)

This coding exercise resulted in sorting adolescent experience according to the following umbrella themes: (i) illness, disease, clinical symptoms, or clinical diagnosis; (ii) feelings or emotions; (iii) some aspect of the self; (iv) behavior; (v) relationships; (vi) cognition; (vii) physical concerns; (viii) expectations or hopes for what medications would do; and, (ix) medication management activities. In the final analytic step these themes were sorted according to the three research questions: illness and treatment perceptions about how medications work; and medication management perceptions.

Coding reliability was established by a process of seven coders independently coding 6 adolescent interviews; this combined effort generated nearly 500 in-vivo codes (themes based on concepts used by the interviewees). Then, the first author and study principal investigator (PI) examined the codes to eliminate redundancy. For example, when the same quotation was given different code names, they were reassigned to a single code. This process eliminated nearly 289 redundant codes, resulting in a ‘master codebook’ of 211 codes based on the first 6 interviews. This master codebook was then used by the coders for the remaining 14 interviews. Coders were instructed to create new codes from the 14 subsequent interviews only if codes in the master codebook failed to fit the new data; the PI then reviewed the code list generated from the 14 interviews and added new codes to the master list. The PI conducted a validity assessment of the final data set by checking that: (i) the codes referring to quotations were consistently applied across all 20 interviews; (ii) codes were appropriately grouped under the thematic categories; and, (iii) themes were appropriately grouped under the three research questions.

RESULTS

**PARTICIPANT DEMOGRAPHICS AND CLINICAL PROFILE**

Twenty youths participated in this study. The mean age was 14.75 years (SD 1.6); 9 were male and 11 female, 8 African American and 12
Euro-American; the mean years of education was 8.85 (SD 1.63). The mean number of prescribed psychotropic medications was 2.35 (SD 1.09) and average age at first prescription 10.35 years (SD 3.01; range 5–15 years). The mean number of prior hospitalizations was 3.4 (SD 2.3, range 0 to 9 times) and the age at first hospitalization 12.78 (SD 1.99).

There was a high rate of psychiatric comorbidity with subjects meeting diagnostic symptom criteria for an average of 2.35 (SD 1.53) psychiatric diagnoses (see Table 1 for summary of psychiatric diagnoses).

The average CGAS (Clinical Global Assessment Scale) score at enrollment was 61.40 (SD 11.83), suggesting ‘variable functioning with sporadic difficulties.’ At the time of enrollment, parents (n = 20) reported adherence ‘all the time’ (n = 13), ‘usually’ (n = 6), and ‘sometimes’ (n = 1). Adolescents (n = 20) self-reported adherence ‘all the time’ (n = 18) and ‘sometimes’ (n = 2).

**Adolescent Experience of Psychotropic Treatment**

*Illness and Medication Treatment Experience*

The TeenSEMI questions that elicited adolescent experiences of mental illness and treatment generated 74 in-vivo codes (linked to 273 quotations). These were compared and sorted to produce seven emergent themes: (i) emotion – references to emotional problems; (ii) diagnosis/disorder/symptom – reference to psychiatric illness, disease, or diagnosis; (iii) self – reference to some aspect of the self as the problem; (iv) cognition/thought – reference to cognitive problems; (v) intersubjective – reference to relationship problems; (vi) body – reference to physical problems, and; (vii) behavior/action – reference to behavioral or school problems. Column 1 of Table 2 gives examples of the themes and related adolescent responses.

<table>
<thead>
<tr>
<th>K-SADS-PL DSM-IV Diagnosis</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mood disorder</td>
<td>15</td>
<td>75</td>
</tr>
<tr>
<td>ADHD</td>
<td>12</td>
<td>60</td>
</tr>
<tr>
<td>Disruptive behavioral disorder</td>
<td>7</td>
<td>35</td>
</tr>
<tr>
<td>Substance abuse disorder</td>
<td>2</td>
<td>10</td>
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<td>Anxiety disorder</td>
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<td>10</td>
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<tr>
<td>Eating disorder</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Panic disorder</td>
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<td>5</td>
</tr>
<tr>
<td>Psychotic disorder</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Other disorders</td>
<td>5</td>
<td>20</td>
</tr>
</tbody>
</table>

*Percentages sum to > 100 due to comorbidity*
### TABLE 2
Adolescent perceptions of medications – selected quotations

<table>
<thead>
<tr>
<th>Theme</th>
<th>Need for Medication Treatment</th>
<th>How Medications Work</th>
<th>Adherence to Medication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis/Disorder/Symptom</td>
<td>'it was for anxiety attacks and depression'</td>
<td>'They balance off my mood swings to where I won't have as many.'</td>
<td>[negative]² 'I don't want to get hooked on it or anything like that.'</td>
</tr>
<tr>
<td>Emotion</td>
<td>'I think it's mostly because I had a really, really bad attitude.'</td>
<td>'... when I get angry, make me not like want to hurt my little sister cause she just gets on my nerves.'</td>
<td>[positive] 'At first my parents told me to, but once I see that that actually help, I take it.'</td>
</tr>
<tr>
<td>Expectation/Hope</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self</td>
<td>'I'm a mental case.'</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavior/Action</td>
<td>'... because I was having problems, real problems in school.'</td>
<td>'It's making me act better.'</td>
<td>[positive] 'It's my sleeping pill.'</td>
</tr>
<tr>
<td>Intersubjective</td>
<td>'... they thought that I was disrespecting them if I told them no.'</td>
<td>'I gain a relationship with my family again.'</td>
<td>[negative] 'Oh D, you can't behave? Oh D, you're bad. You're on medicine, cause kids in my school, they'll make fun of you.'</td>
</tr>
<tr>
<td>Cognition/Thought</td>
<td>'... when I wasn't paying attention in school.'</td>
<td>'... listening and focusing and stuff.'</td>
<td>[positive] 'I think it actually helps me to focus and I think that anger is more like in my own hands.'</td>
</tr>
<tr>
<td>Body</td>
<td>'... like headaches and stomachache.'</td>
<td>'It's supposed to like balance out something in your brain.'</td>
<td>[negative] 'I don't want to take it trying to help something else and then it messes up another thing.'</td>
</tr>
<tr>
<td>Management</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes:
1 Assigned by sorting in-vivo codes and quotations into a common category.
2 Coders read adolescent responses or quotations and assigned them a positive or negative code based upon the adolescents' positive or negative attitude toward the medication. See examples in this table.
Some adolescents understood their need for help and the need for medication as 'getting into trouble,' as 'swings in moods,' as problems in 'concentrating,' and as problems 'getting along with parents.' Others, by saying, 'I am ADD,' or 'I am bipolar,' viewed their need for help as self-defining, while others externalized the diagnosis, saying, 'I have an illness,' or 'I have depression,' or 'it applied to me.'

**How Medication Works**

Adolescent responses to queries about how medications work resulted in the creation of 87 in-vivo codes (linked to 441 quotations). These codes, representing how medications work, were contrasted and sorted, resulting in the identification of six themes: (i) body – how medication affected the body; (ii) emotion – how medication affected feelings and mood; (iii) cognition/thought – how medication affected thinking; (iv) behavior/action – how medication improved schoolwork or decreased aggression; (v) intersubjective – how medication improved relationships with mother, peers, and teachers; and, (vi) expectation/hope – what they wished medications would do for them. Column 2 of Table 2 offers examples of adolescent responses.

In general, adolescents reported that medication helped with sleep, 'to act right,' and 'to do stuff better,' representing a belief that medication produced behavioral change. They described how parents and others influenced their experience and understanding of illness and medication; with this grouping of codes, we identified an intersubjective theme. For example, respondents (7 of 20) said that they learned from psychiatrists, mothers, television, internet, books, movies, and advertisements about how medications worked and what they affected. Among the intersubjective themes one was especially common (13 of 20): medications improved relationships at home, school, or with peers. Emotionally, medications were described as: 'it stabilizes,' 'it levels me,' 'it evens my moods,' 'it calms me down,' and 'it makes me proud of myself.' Adolescents hoped medications would do many things: provide a cure; control their anger. They hoped medications would not stop working, or that they would relieve family stress. They hoped for an easier regimen (e.g., a once a day drink, or patch instead of pills).

**Side Effects**

Adolescent experience with medication side effects was linked to 27 in-vivo codes. Comparison of the shared characteristics of the quotations linked to side effect codes produced two themes: (i) body – how treatment resulted in unwanted physical concerns and; (ii) emotion – how treatment resulted in unwanted feelings. Answers commonly associated with
physical/bodily themes were: sleepiness, stomachache/heartburn, headache, hand tremors, dizziness, reduced appetite, interference with taste, weight gain, and blurred vision. Other quotations were linked to codes that were grouped under an emotional theme: worries about being too happy or hyper, worries about becoming dependent on the medication, worries about feeling high, and worry that the medications made them 'act differently.' Only 3 of the 20 reported minimal or no side effects.

Perceptions of Adherence
Forty-eight in-vivo codes (linked to 180 quotations) referenced adherence experience; these were compared and grouped under seven themes: (i) expectation/hope – how medication had either disappointed or produced the desired effect; (ii) intersubjective – how relationships had improved; (iii) emotion – how feelings had improved or not; (iv) body – negative or positive physical concerns; (v) management – the tedious nature of daily management; (vi) cognition/thought – negative or positive; and, (vii) behavior/action – better grades and fewer behavioral problems (see Column 3 of Table 2 for examples). Although more adherence experiences were coded as negative (30 of 48 negative), positive feelings were frequently (18 of 48 positive) reported. Negative experience with medication was described as; bodily side effects, difficulties remembering to take medication and worries about dependency. Positive feeling, on the other hand, was linked to improvements in the quality of family, peer, and school relationships, emotional stability, and feeling that medication worked as hoped.

In summary, themes that emerged suggest that adolescents refer to their bodies, emotions, behavior, thoughts, self, and expectation/hope when making sense of medication treatment. It also appears that perceptions of medication are drawn heavily from parents and doctors; however, peers, siblings, counselors, Internet, television, and movies were also identified and could be significant interpersonal influences upon overall experience.

Case Illustration
Alicia, a 14-year-old Caucasian female in a regular eighth grade classroom (on an Individual Education Plan), was prescribed an antidepressant at age twelve and at the time of the interview was taking an antipsychotic and a mood stabilizer. The K-SADS diagnostic interview suggested a group of Bipolar 1 symptoms, euthymic, with rapid cycling. The diagnostic interview also suggested secondary diagnoses of ADHD-combined type, separation anxiety, oppositional defiant disorder, and conduct disorder. Alicia and her mother reported adherence to the medication regimen 'all of the time.' And her Clinical Global Assessment score was near the
mid-range, suggesting that at school, with peers and family, she had normal functioning with only occasional problems.

In response to TeenSEMI questions about the need for treatment (e.g., can you tell me in your own words, why you see the psychiatrist?), Alicia reported:

I think the reason why I’m going is because I have bipolar. I felt like I was doing fine, but I guess there were kind of different things going on. (coded Diagnosis/Disorder/Symptom)

I think it’s mostly because I had a really, really bad attitude and if I didn’t like what they [parents] said, I didn’t want to hear it, and if I didn’t like it and they kept telling me, I’d start screaming, so they knew something was wrong with me. (coded Emotion)

Because when I have a bad episode, I tend to black out, I don’t remember things . . . like these glasses. I took them when I was mad and I twisted them all up and . . . I don’t remember doing it at all. My mom just told me. (double coded, Body and Behavior)

Like I would have outbursts every single day. (coded Emotion)

[what do you think caused you to have these concerns?] I’m not sure if this is really it, but the move [referring to moving out of grandma’s house after her death], because that just made my emotions go absolutely crazy. I mean I’ve lived in that house my whole life up to the 4th grade . . . That was my grandma’s house before she died, I mean, and I met my best friend at that house, and it just kind of felt like, oh my god. Look I’m just totally leaving, and it just made me really upset and made my emotions go crazy. (coded Emotion)

Well that’s when [six months after seeing a psychiatrist the first time] I first started to hear, they started saying bipolar, but also, I just remember two months into that, they had me ODD [oppositional defiant disorder], separation anxiety, and mania. (coded Diagnosis/Disorder/Symptom)

He [psychiatrist] kind of told my mom, before he told me, and then my mom sat down and explained it to me and we went and got some books from the library and we pretty much just read up on them and seen what they really were. (coded Intersubjective)

My best friend’s twin brother . . . we became really good friends . . . we [her friend] would always make jokes about him and laugh at him because he was bipolar . . . and he kind of explained to me what it was and how you have to just deal with it. (coded Intersubjective)

At first I was like, ‘no, I can’t be bipolar.’ That’s just not me. I don’t want to be it and then when I started actually seeing what was really going on, I’m just like, oh my god, I can’t believe I just said that I wasn’t this, and now I am. (doubled coded Diagnosis/Disorder/Symptom and Self)
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[so will the diagnosis of bipolar go away, do you think, over time?] No . . . its there to stay. (double coded Diagnosis/Disorder/Symptom and Self)

I only thought it was people like really crazy, and you know like the hobo thing you see on the street singing to themselves and just walking back and forth, that’s what I thought they were. Really all of it. Like I was able to relate to every single part of it. (coded Self)

I also still have separation anxiety. [and where did you get that name?] The CLINIC. I got that from The CLINIC, who told my mom, then my mom told me . . . She explained it to me . . . I didn’t realize like what separation anxiety is, and then she’s just all like, ‘well do you remember when grandma died?’ And I go, ‘yeah.’ ‘Do you remember how you won’t let that go and you probably will never let that go?’ I’m like ‘Yeah . . . that is what separation anxiety is.’ [and that again felt true to you?] yeah. (double coded, Self and Diagnosis/Disorder/Symptom)

In response to questions about how medications work, Alicia offered the following:

I started taking medicine and I would see a total different person when I took the medicine. I mean I wasn’t so angry and I was able to have a good time and laugh and just have fun. (triple coded Emotion, Self, and Intersubjective)

[what went through your mind when medication was first suggested?] I felt like they thought I was crazy. (coded Self)

[do you recall what that first medication was called?] Oh I can’t remember it. I know it’s always on TV with the little happy dot thing. [how did that feel to you when you saw something on TV that you were taking?] I just made fun of it a lot, like me and my mom. Like if I didn’t feel like taking it, my mom was like, ‘go take your happy dot pill.’ (coded Intersubjective)

[if a medication could do anything you wanted for the concerns you have mentioned, what would you wish it could do for you?] Nothing for me, mostly for my family. I feel that way so they won’t have to go through all the pain that they had to go through (coded Intersubjective)

[what do you think the (antipsychotic) actually does for you?] It’s my sleeping pill . . . I take it and I kind of get all goofy for like an hour, and then I’ll be really, really hungry and I’ll eat all these calories, then I’ll go to bed. [so you couldn’t sleep before the antipsychotic?] I could, just not as well. Like if I heard my dog walking pass my bedroom, I’d wake up and didn’t know what to do, and I’d lie there for like two hours trying to go back to sleep, because I can’t fall asleep without my TV on. So I’d turn on my TV and just lie there, watch TV and not be able to go back to sleep. [so the antipsychotic helps you sleep all through the night?] yeah. (coded Behavior)
[what do you think the (mood stabilizer) actually does for you?] It balances off all my . . . mood swings to where I won't have as many. It's like with my brother, he'll get me mad, and before [medication] I would just straight up and hit him . . . I don't get as aggravated . . . I mean when I was off the medicine, I would kind of like always get into trouble for aggression. I got in a fight at school. I got suspended. I got put in the court system. I beat another girl up outside of school. (coded Behavior and Emotion)

[what are some things that medication can't do for you?] Right now I'm loving life. I have great friends. I mean there's nothing better that I can ask for right now. It can't just totally keep me happy all the time. It's just the part that everybody has . . . it is normal to get a little annoyed . . . I mean it [medication] controls it [aggression] but it does not take all of it away.' (coded Emotion and Intersubjective)

[what do you think your mother or father want medication to do for you?] Right now my mom likes the medication on me. I mean she even said she couldn't ask for anything better . . . My dad, honestly, doesn't want me on medication, because when he was younger, he was on medication. It didn't work for him. But my mom said that it works, and he said that he's starting to know a difference, but he's still kind of like, 'well I still don't want her on medication.' (coded Intersubjective)

[how long do you think others believe you should take your current medication?] I don't want to take them at all, but it's something I have to do . . . the rest of my life . . . They told me I'm going to be bipolar for the rest of my life and I'm going to be stuck on medication. [who is they?] My mom, dad, my doctor, my psychiatrist, my counselor, my teachers, my [school] principal. (coded Intersubjective)

[some people believe that we should not take medication and fix ourselves, what do you think about that?] I thought the same way. I mean it's kind of like I was getting brainwashed by one of my friends, and she was like, 'by 2010 almost everybody in the world's going to be on medicine,' and then I started to see the real truth, and it's just I feel like why would they put me on it if it really didn't work? I mean are they trying to fool me or get my insurance money or something? But then I really found out. (coded Intersubjective)

How are we to understand the clinical/diagnostic and psychosocial referents in Alicia's narrative? First, while she was 'given' diagnoses for bipolar and separation anxiety, clinicians turned to her mother to offer explanatory accounts: 'He [psychiatrist] kind of told my mom, before he told me, and then my mom sat down and explained it to me.' And while Alicia internalized an illness/disorder identity – I am bipolar ('now I am') – she also produced a distance between herself and the diagnosis by stating that the diagnosis ('it') had been given to her ('they started saying'; 'they had me'). Moreover, while bipolar was something she had 'for life,'
assigned to her by clinics and psychiatrists, she also saw a possible connection to the death of her grandmother and the move from her grandmother's house. She said, 'it just made my emotions go absolutely crazy.' And while she thought medication worked on her aggression, it seemed also to leave some part of it unaddressed.

Alicia wondered whether her friend was correct to think that by 2010 everybody in the world would be on medication? She seemed to be saying: 'if everybody is on medication, and I am on medication, then I am like everyone.' This was, however, more than a simple normalization of experience. It is in this complex, intersubjective dynamic that Alicia joined others to co-produce the meaning of the medication experience. Indeed, this intersubjective dynamic is to be found in all 20 interviews. The clinical implications, we believe, are far-reaching. Psychiatrists, for example, must attend not only to prescribing the antidepressant, they must grasp how Alicia, and her mother make sense of the 'happy dot pill.' The television advertisement referred to in the narrative above suggests that medication targets neurotransmitters and depressive/behavioral symptoms; but mother and daughter are equally influenced by the drug's implied power to create happiness. Alicia and mother found humor in the commercial by joking about the tedious nature of daily medication management. Of the intersubjective influences on medication experience perhaps most significant was Alicia's belief that taking medication both pleased her mother and resulted in fewer fights with her brother. Alicia's motivation to adhere to the medication was related in part to her perception that it helped make peace in the family. This finding suggests that medicating adolescents is symbolically medicating a family because the effects of medication generate meanings that implicate an entire family system (Chubinsky & Rappaport, 2006; Oldani, 2009; Rappaport & Chubinsky, 2000).

**Discussion**

Alicia's medication experience presents several possibilities for further inquiry. Peter Conrad (2007), for example, has recently looked at how social and psychological problems are increasingly framed by and acted upon through biomedical assumptions. Drawing on such work, one might explore the relationship between medicalization and psychiatric medications by examining how Alicia simultaneously adopts and accepts both the bipolar diagnosis and psychosocial explanations of her difficulties. For example, we might ask how psychiatric medicalization produces fundamentally new possibilities for conceptions of self, as determined by the medication experience. Moreover, asking such questions can highlight the analytical limitations of concepts such as medicalization and the globalization of pharmaceuticals. Thus while one can easily join Alicia in
imagining a world in which everyone is on psychiatric medications, globalization, like medicalization, is a not a sufficiently rich concept to provide an adequate account of how individuals ultimately make sense of their medication experiences. These concepts, for example, would not help us conceptualize how for Alicia the ubiquity of medication becomes a potential defensive projection aimed at normalizing stigma or shame about her illness or medication experience. David Karp shows in his work with teenagers how anti-depressants in schools produced an intersubjective experience of stigma (Karp, 2006). Whichever direction the cause and effect might run in these instances, there is little doubt that for Alicia the hoped-for symptom-focused biomedical model is just one of many ways in which she makes meaning of psychiatric medications.

Over the set of 20 adolescent respondents, personal and interpersonal themes of adolescent psychotropic treatment might be understood as different points of view through which adolescents understand and take action related to: their illness concerns; their need for medication treatment; their perceptions of how medications work; their responses to parental and other influences upon medication treatment; and their everyday management activities. The theme of expectation and hope seems particularly central to their experience. It is in the space between the successful and disappointing medication treatment that adolescents wonder: ‘why take medications,’ ‘what will they do for me,’ ‘will they harm me,’ and ‘how will I manage them.’ Our findings suggest that adolescents will deploy one or several personal and interpersonal life domain dimensions to answer these questions and in doing so make psychotropic treatment meaningful.

As is the case with all of those interviewed for this study, Alicia’s particular diagnosis and medication experience is mediated by complex social dynamics. Observation and interpretation of adolescent medication effects are shaped by family, community, cultural, and personal belief and attitude toward: the diagnosed illness; how diagnoses are made; and the treatment, including the nature of the relationship between practitioner and treatment recipient. Our model for representing adolescent medication experience and management is summarized in Figure 1. The model is comprised of five elements of a medication experience, represented vertically (highlighted in gray) as the socio-cultural dimension: (i) problem, (ii) prescription assessment, (iii) access and payment, (iv) monitoring and interpreting effects, and (v) reporting effects. Furthermore, pharmaceutical interests, insurance/payment policies, and the organization of local mental health services set the parameters for the medication experience. For example, the local service provider may be resource depleted or influenced by a single or reductionist model of the relationship between mind and body. Horizontally we have depicted the
<table>
<thead>
<tr>
<th>Personal Interpersonal Dimension</th>
<th>Subjective</th>
<th>Subjective</th>
<th>Subjective</th>
<th>Intersubjective</th>
<th>Social Relations of Medication Management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Socio-cultural Dimension</td>
<td>Emotion</td>
<td>Cognition</td>
<td>Body</td>
<td>Beliefs and attitudes about the illness and diagnosis</td>
<td>Parent, Peer, Teacher, Clinician expectations</td>
</tr>
<tr>
<td>(1) Problem and diagnosis</td>
<td>What emotions get indexed to a diagnosis?</td>
<td>What beliefs and attitudes get indexed to a diagnosis?</td>
<td>How is the body indexed to a diagnosis?</td>
<td>Beliefs and attitudes about medication producing the desired effect?</td>
<td>Daily, who does what, when?</td>
</tr>
<tr>
<td>(2) Medication prescription and clinically hoped-for effects</td>
<td>What emotions get indexed to desired effects?</td>
<td>What beliefs and attitudes get indexed to desired effects?</td>
<td>How is the body indexed to a desired effect?</td>
<td>Beliefs and attitudes about payment and service access?</td>
<td>Periodically, who decides the category and dosage for or with the adolescent?</td>
</tr>
<tr>
<td>(3) Access and payment</td>
<td>What emotions get indexed to payment and service access?</td>
<td>What beliefs and attitudes get indexed to paying and service access?</td>
<td>How the body is indexed to paying and service access?</td>
<td>What are the feelings, thoughts, and beliefs about compliance, monitoring, and the actual effects of medication?</td>
<td>On a regular basis, how are the medications paid for and who assures access to medication?</td>
</tr>
<tr>
<td>(4) Monitoring adherence and interpreting gap between hoped for and actual effects, including unintended side effects</td>
<td>What emotions can be indexed to compliance, expected, and actual effects?</td>
<td>What beliefs and attitudes get indexed to compliance, expected, and actual effects?</td>
<td>How is the body indexed to compliance, expected, and actual effects?</td>
<td>Among all involved, who reports medication effects to whom?</td>
<td>On a daily basis: Who monitors compliance? Who monitors actual effect? Who monitors unintended side effect?</td>
</tr>
<tr>
<td>(5) Reporting effects, including unintended side effects</td>
<td>How are medication effects on emotions reported?</td>
<td>What beliefs and attitudes about effects are reported?</td>
<td>How are medication effects on the body reported?</td>
<td></td>
<td>On a daily basis: Who reports what to whom?</td>
</tr>
</tbody>
</table>

Figure 1 Socio-cultural, personal, and interpersonal matrix of adolescent medication experience and management.
subjective (i.e., personal) and intersubjective (i.e., interpersonal) dimensions of the adolescent psychopharmaceutical experience.

The subjective aspect of medication treatment has two dimensions and addresses the degree and nature of involvement, passive or active (Longhofer, Floersch, & Jenkins, 2003b), in making sense of the biopsychosocial domains; Alicia, for example, was actively engaged in making a psychosocial claim about her illness: she wondered about the effect of her grandmother's death on her intense affect. And while one might see this as active resistance to the biological diagnosis, Alicia just as actively embraced her bipolar diagnosis: she engaged with her mother to determine the cause of her affective storms. Moreover, she reported that medication reduced aggression and also linked the medication's effect to an acceptance of the correct diagnosis, '... it balances off all my... mood swings to where I won't have as many.' Alicia's references to the biopsychosocial domains of emotion, cognition, and body show us the personal and interpersonal dynamic of her medication experience and the sociocultural milieu organizing her experiences around DSM-IV categories and medication treatment. The aggregate data and case illustration remind us of the danger of reducing our assessment of medication treatment to its biological or clinical effects; assessment must include attention to extra-clinical, sociocultural effects.

The intersubjective dimension also refers to how passively or actively the adolescent engages others, (i.e., parents, peers, teachers, clinicians, and friends) the Internet, popular magazines or culture, and libraries in gathering information that shape how they make sense of the psychotropic experience. Alicia, for example, was influenced by the Zoloft commercial, as well as by a peer's brother who had been diagnosed with bipolar disorder. She also took medication, in part, to please her mother. At the same time, her father remained skeptical of the pharmacological treatment. Indeed many adolescents in this study reported that fathers were not engaged in treatment decisions, and were similarly ambivalent. The influence of skeptical fathers on their children presents a challenge: when parents disagree over medication use, how does this affect the medication experience? 5

The system of medical, clinical diagnosis produces a particular intersubjective field for making meaning of everyday medication experience. And while it might be easy for some to imagine that psychiatric diagnoses are made based solely on 'detecting signs that point to objective, measurable parameters' (Verhaeghe, 2004, pp. 17–18) in practice psychodiagnostics always requires interpretation. Although at the time of Alicia's interview bipolar disorder was the principal diagnosis, she had been given several diagnoses over the years. Clinicians prescribing medications are obligated to connect the suggested use and type of drug
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(e.g., anti-psychotic, mood stabilizer, psychostimulant, etc.) to particular diagnoses. Yet, these data suggest that it does not necessarily follow that the recipient accepts the diagnosis and the connection between a specific disease/disorder and its associated medication. Diagnosing youth, moreover, presents serious challenges. Alicia’s history of multiple diagnoses illustrates this challenge and raises the question: which diagnosis did she identify with and why?

Table 3 compares the self-reported diagnosis of the 20 participants with that of the K-SADS-PL. The comparison shows that 13 of 20 adolescents did not report a disjuncture between their diagnostic understanding and the K-SADS-PL, a standard symptom-based assessment. For 7 (highlighted in gray), however, there was a disjuncture, raising questions about how they experienced the gap between the clinician’s diagnostic interpretations and their own understandings of the problem and associated medication treatment.

Conclusion

For most people who take aspirin for headaches, the hoped-for effect is credited to the power of the drug. Between the expected (hoped-for or desired) and the experienced effects of medication, there exists a phenomenological, subjective and intersubjective gap (Longhofer & Floersch, 2004; Longhofer, Floersch, & Jenkins, 2003a). When medicine is believed to be the agent that delivers the expected effect, the gap between desired and experienced effects is narrowed. In such cases, patients are likely to interpret treatment effects as tangible and focused. On the other hand, this gap between expectations and experience may be quite large when the anticipated effects of a medication are less well defined and when others assert their expectations (Floersch, 2002). Thus, in relation to reducing or eliminating psychiatric symptoms like depression, anxiety, and irritability, the expected effects may be elusive, transient, or difficult to pinpoint. In the present study, Alicia, for example, regarded the medication’s role in reducing aggression in positive terms; yet she also recognized, ‘it doesn’t take it all away.’ She seemed to be asking: how much aggression is normal? Or: how much is left over after the medication takes care of its portion? There was another gap between her expectation that the medication will help her and that it would help others: ‘Nothing for me, mostly for my family.’ This gap represents a subjective and intersubjective space within which the medication recipient (or others in their network) observes, monitors, and interprets. Meanwhile, adolescents’ interpretations of medication effects are always embedded in the broader context of sociocultural factors related to mental health services and biopsychiatry.
### TABLE 3
Participant self-report diagnosis compared with research, KSADS-PL diagnosis

<table>
<thead>
<tr>
<th>N = 20</th>
<th>Self-Report Diagnosis</th>
<th>Primary KSADS-PL Diagnosis</th>
<th>Second KSADS-PL Diagnosis</th>
<th>Third KSADS-PL Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Bipolar</td>
<td>Bipolar</td>
<td>ADHD</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Seizures, does not know</td>
<td>Schizophrenia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Bipolar</td>
<td>Bipolar</td>
<td>Separation Anxiety</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>ADD</td>
<td>ADHD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Bipolar, ODD, Anxiety</td>
<td>Bipolar</td>
<td>Conduct Disorder</td>
<td>ODD</td>
</tr>
<tr>
<td>6</td>
<td>Depression</td>
<td>Major Depressive Disorder</td>
<td>PTSD</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Bipolar, ADD, Depression</td>
<td>Bipolar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>ADHD, ODD</td>
<td>Bipolar</td>
<td>ADHD</td>
<td>ODD</td>
</tr>
<tr>
<td>9</td>
<td>Depression, Bipolar</td>
<td>Major Depressive Disorder</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Bipolar</td>
<td>Bipolar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>ADHD, Depression</td>
<td>Major Depressive Disorder</td>
<td>ADHD</td>
<td>Panic Disorder</td>
</tr>
<tr>
<td>12</td>
<td>Mood Disorder</td>
<td>Bipolar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Depression, Eating Disorder</td>
<td>Major Depressive Disorder</td>
<td>Eating Disorder</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Bipolar, ADHD, Depression, Anxiety</td>
<td>Substance Induced Mood Disorder</td>
<td>ADHD</td>
<td>ODD</td>
</tr>
<tr>
<td>15</td>
<td>ADHD</td>
<td>Bipolar</td>
<td>ADHD</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Forgot – does not know</td>
<td>Eating Disorder</td>
<td>Avoidant D/O</td>
<td>Enuresis</td>
</tr>
<tr>
<td>17</td>
<td>ADD</td>
<td>Major Depressive Disorder</td>
<td>ADHD</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Did not give a name</td>
<td>ADHD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Depression, ADD</td>
<td>Bipolar</td>
<td>ADHD</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>ADD</td>
<td>ADHD</td>
<td>Enuresis</td>
<td></td>
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</table>
ACKNOWLEDGEMENTS

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NOTES

1. This outpatient research protocol was reviewed and approved by the University of Hospitals Case Medical Center Institutional Review Board for Human Investigation. The parents/guardians of the research participants provided written informed consent and all adolescents provided written informed assent prior to study participation. The interviews conducted under the auspices of this study took approximately six hours. Parents received $50 and adolescents $65, respectively as honoraria.

2. Prior to administering the diagnostic assessment, the rater met adequate inter-rater reliability standards (kappa > .85) on five consecutive interviews while observing a trainer-rater and on five consecutive interviews while leading the interview; a rater's kappa of ≥ 85 indicates that eighty-five out of hundred conclusions would reliably match other raters trained with the same protocol.

3. The type of coding procedure used in this analysis is a synthesis of the following grounded theory approaches: Boeije, 2002; Charmaz, 1990, 2006; Glaser & Strauss, 1967; Muhr, 1993; Sivesind, 1999.

4. Indirect support for these findings includes research that has emphasized that adult experience is mediated by culture, mental health systems, and medicalization processes (Conrad, 2007; Floersch, 2002; Jenkins et al., 2005; Karp, 2006; Kirmayer, Young, & Robbins, 1994; Kleinman 1988).

5. Results from one clinical drug trial have noted that a medication's intended effect was moderated by the degree of family conflict (see Townsend, Demeter, Youngstrom, Drotar, & Findling, 2007).

REFERENCES


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Adolescent Experience of Psychotropic Treatment

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Abstract  Despite growing concern over the treatment of adolescents with psychiatric medications, little research has examined youth understandings and interpretations of mental illness and psychotropic treatment. This article reports the exploratory findings of semi-structured and open-ended interviews carried out with 20 adolescents diagnosed with one or more psychiatric disorders, and who were currently prescribed psychiatric medications. Grounded theory coding procedures were used to identify
themes related to adolescent subjective experience with psychiatric medications. The categories identified are interpreted as different points of view through which adolescents understand and take action upon their illness concerns; their need for medication treatment; their perceptions of how medications work; their responses to parental and other influences upon medication treatment; and, their everyday management activities.

Key words adolescent • medication management • psychiatric medication • qualitative research • subjective experience,

Introduction

Concern regarding adolescent mental health treatment with psychiatric medication has intensified among researchers, families, and practitioner groups, as the rate at which youth are prescribed psychotropic agents has increased over the last 20 years (Cooper et al., 2006; Olsson, Marcus, Weissman, & Jensen, 2002; Thomas, Conrad, Casler, & Goodman, 2006; Wong, Murray, Camilleri-Novak, & Stephens, 2004; Zito et al., 2003). Given this increasing use, researchers have called for studies of safety and efficacy because, it is argued, youths may respond to psychiatric medications differently than adults (Findling & Wiznitzer, 2003). Yet despite increasing scientific investigation into the effectiveness and tolerability of psychotropic agents in young people, there are limited data on how adolescents prescribed psychotropic agents subjectively experience medication treatment. We should not assume that youth have understood their illness, made sense of their medication treatment, and have adhered to a regimen as have adults. Indeed, social scientists have emphasized the many ways, active and passive, in which adults understand mental illness, diagnosis, medication treatment, and adherence (Charmaz, 1990; Conrad, 1985; Jenkins, 1994; Karp, 1996; Kleinman, 1988). Among adults with major depression, for example, David Karp (1996, p. 102) concluded that, ‘... the experience of taking antidepressant medications involves a complex and emotionally charged interpretive process in which nothing less than one’s view of self is at stake.’ Understanding the interpretive or psychosocial aspect of youth psychotropic treatment, as Karp has argued for adults, may improve youth medication treatment. Thus, while the knowledge gap about the safety and efficacy of youth psychotropic treatment is gradually being addressed, we must now turn our attention to how youth make the treatment experience meaningful (Floersch, 2003).

Health research has demonstrated that adolescents draw upon personal perceptions, beliefs, and meanings in their experience of medical interventions. For example, adolescents modify medical advice about asthma when they believe that their knowledge of physical events supersedes the knowledge of doctors (Buston & Wood, 1999; Jessop & Rutter, 2003).
Others report that adolescents discontinue asthma medication when they are unaware of specific bodily symptoms such as dyspnea (van Es et al., 1998). It has been shown that adolescents with chronic asthma stopped medication when they thought it was ineffective, or when believed they did not have the illness (Buston & Wood, 1999; van Es et al., 1998). Research on diabetic and asthma patients has found that adolescents may also assert autonomy by resisting standard treatment (Adams, Pill, & Jones, 1997; Kyngas & Hentinen, 1995) and may not adhere to prescribed treatments when they do not feel like taking medication (Hanna & Guthrie, 2000; van Es et al., 1998). Similarly, HIV-positive adolescents report how they avoid antiretroviral regimens when they feel healthy (Pugatch, Bennett, & Patterson, 2002). Cromer and Tarnowski (1989) show how adolescents treated for general medical conditions stop medications that prevent illness progression or episodic exacerbations when interventions lack the behavioral reinforcement of immediate relief from physical symptoms. In short, the literature on illness beliefs in medicine suggests that adolescents respond to medication treatment in profoundly personal ways that influence adherence and treatment effectiveness.

In this article, we report qualitative findings from a larger mixed-method study of adolescent psychotropic experience. Our aim here is to use grounded theory coding procedures to identify thematic categories adolescents use in making meaningful the psychotropic experience, specifically: (1) how do adolescents internally represent illness concerns and need for medication treatment? (2) how do adolescents think medications work? and, (3) how do adolescents perceive their participation in routine medication management activities?

**Method**

**Sample**

Subjects were recruited through discussions with professional staff, and fliers and posters aimed at patients seen within the outpatient clinic in the Division of Child and Adolescent Psychiatry at a university hospital, community mental health outpatient settings, and an alternative high school for adolescents with emotional and behavioral problems. Only adolescents, ages 12 to 17, meeting DSM-IV criteria for a psychiatric illness and currently being prescribed a psychotropic medication were eligible. Participants were excluded when parents reported that the adolescent had not taken psychiatric medication at least once in the past 30 days. Moreover, adolescents with developmental disability (i.e., IQ lower than 70), a pervasive developmental disorder, seizure disorder, or an organic brain disorder, were not enrolled.¹
Measures

Interviews for this study were carried out using the Teen Subjective Experience of Medication Interview (TeenSEMI), a semi-structured interview instrument, adapted from the adult version. The adult SEMI was designed to obtain narrative data about medication treatment from those diagnosed with schizophrenia (Jenkins, 1997; Jenkins et al., 2005). The TeenSEMI was produced by eliminating or modifying questions for adults (e.g., questions about work, marriage, and recovery) and developing age-relevant questions (e.g., questions about school, peer, and family interactions). The final interview schedule, approximately 150 questions, included 9 categories related to illness, treatment, and medication: (i) treatment, illness, and medication history; (ii) perceptions of medication; (iii) managing, monitoring, reporting of medication experience; (iv) parent and adolescent interaction regarding medication management; (v) illness and medication stigma; (vi) adolescent and school interactions regarding medication management; (vii) adolescent and peer interactions regarding medication management; (viii) access to mental health services regarding medication experience; and, (ix) ethnicity, gender, and religious influences regarding medication experience.

In addition to data produced with the semi-structured instrument, we collected adolescent and family demographics and psychiatric/medication treatment history. The Kiddie Schedule for Affective Disorders for School-Age Children Present and Lifetime Version (K-SADS-PL) (Kaufman et al., 1997) was used to determine participant diagnoses and the Child Global Assessment Scale (Shaffer et al., 1983) was used to assess overall functioning at home, with peers, and in school. The K-SADS-PL, a semi-structured research interview, has been used as a ‘gold’ standard to assign diagnostic categories in clinical drug trials or psychosocial intervention studies. It assesses symptom constellations according to DSM-IV psychiatric diagnoses in pediatric patients based on information provided by youth and parents or caregivers. The K-SADS-PL diagnostic interviews were conducted by a researcher (second author) trained as a ‘rater’ to administer the instrument. The use of the K-SADS-PL does not resolve the many issues related to diagnostic validity because symptom-based diagnostic systems are known to be culturally and historically sensitive (Horwitz & Wakefield, 2007; Kirk & Kutches, 1992). For example, controversy exists over whether or not bipolar illnesses are accurately applied to youth (Moreno et al., 2007; Smith, 2007). In our research, the use of the K-SADS-PL meant that the researcher/rater followed the protocols for symptom-based diagnosis and when the outcome was bipolar, for example, trained raters (with a kappa $\geq 85$) would have agreed with the diagnosis 85% of the time.
Data Analysis

In analyzing the data we assigned in-vivo code names using the actual words of the adolescent; the in-vivo codes were grouped by themes that emerged from comparing their shared characteristics. The specific grounded theory coding steps we utilized consisted of: (i) focused coding, which assigned in vivo codes that reflected data content; (ii) constant comparison of the focused codes, subsequently sorted by similar themes; and, (iii) axial coding, connecting the findings from steps one and two by sorting the discovered themes under broader umbrella categories and specifying how they relate to one another.³

This coding exercise resulted in sorting adolescent experience according to the following umbrella themes: (i) illness, disease, clinical symptoms, or clinical diagnosis; (ii) feelings or emotions; (iii) some aspect of the self; (iv) behavior; (v) relationships; (vi) cognition; (vii) physical concerns; (viii) expectations or hopes for what medications would do; and, (ix) medication management activities. In the final analytic step these themes were sorted according to the three research questions: illness and treatment perceptions about how medications work; and medication management perceptions.

Coding reliability was established by a process of seven coders independently coding 6 adolescent interviews; this combined effort generated nearly 500 in-vivo codes (themes based on concepts used by the interviewees). Then, the first author and study principal investigator (PI) examined the codes to eliminate redundancy. For example, when the same quotation was given different code names, they were reassigned to a single code. This process eliminated nearly 289 redundant codes, resulting in a ‘master codebook’ of 211 codes based on the first 6 interviews. This master codebook was then used by the coders for the remaining 14 interviews. Coders were instructed to create new codes from the 14 subsequent interviews only if codes in the master codebook failed to fit the new data; the PI then reviewed the code list generated from the 14 interviews and added new codes to the master list. The PI conducted a validity assessment of the final data set by checking that: (i) the codes referring to quotations were consistently applied across all 20 interviews; (ii) codes were appropriately grouped under the thematic categories; and, (iii) themes were appropriately grouped under the three research questions.

Results

Participant Demographics and Clinical Profile

Twenty youths participated in this study. The mean age was 14.75 years (SD 1.6); 9 were male and 11 female, 8 African American and 12
Euro-American; the mean years of education was 8.85 (SD 1.63). The mean number of prescribed psychotropic medications was 2.35 (SD 1.09) and average age at first prescription 10.35 years (SD 3.01; range 5–15 years). The mean number of prior hospitalizations was 3.4 (SD 2.3, range 0 to 9 times) and the age at first hospitalization 12.78 (SD 1.99).

There was a high rate of psychiatric comorbidity with subjects meeting diagnostic symptom criteria for an average of 2.35 (SD. 1.53) psychiatric diagnoses (see Table 1 for summary of psychiatric diagnoses).

The average CGAS (Clinical Global Assessment Scale) score at enrollment was 61.40 (SD 11.83), suggesting 'variable functioning with sporadic difficulties.' At the time of enrollment, parents (n = 20) reported adherence 'all the time' (n = 13), 'usually' (n = 6), and 'sometimes' (n = 1). Adolescents (n = 20) self-reported adherence 'all the time' (n = 18) and 'sometimes' (n = 2).

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Illness and Medication Treatment Experience

The TeenSEMI questions that elicited adolescent experiences of mental illness and treatment generated 74 in-vivo codes (linked to 273 quotations). These were compared and sorted to produce seven emergent themes: (i) emotion – references to emotional problems; (ii) diagnosis/disorder/symptom – reference to psychiatric illness, disease, or diagnosis; (iii) self – reference to some aspect of the self as the problem; (iv) cognition/thought – reference to cognitive problems; (v) intersubjective – reference to relationship problems; (vi) body – reference to physical problems, and; (vii) behavior/action – reference to behavioral or school problems. Column 1 of Table 2 gives examples of the themes and related adolescent responses.

**Table 1**

<table>
<thead>
<tr>
<th>K-SADS-PL DSM-IV Diagnosis</th>
<th>n</th>
<th>%*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mood disorder</td>
<td>15</td>
<td>75</td>
</tr>
<tr>
<td>ADHD</td>
<td>12</td>
<td>60</td>
</tr>
<tr>
<td>Disruptive behavioral disorder</td>
<td>7</td>
<td>35</td>
</tr>
<tr>
<td>Substance abuse disorder</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Anxiety disorder</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Eating disorder</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Panic disorder</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Psychotic disorder</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Other disorders</td>
<td>5</td>
<td>20</td>
</tr>
</tbody>
</table>

*Percentages sum to > 100 due to comorbidity
### TABLE 2
Adolescent perceptions of medications – selected quotations

<table>
<thead>
<tr>
<th>Theme</th>
<th>Need for Medication Treatment</th>
<th>How Medications Work</th>
<th>Adherence to Medication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis/Disorder/Symptom</td>
<td>‘it was for anxiety attacks and depression’</td>
<td>‘They balance off my mood swings to where I won’t have as many.’</td>
<td>[negative](^2) ‘I don’t want to get hooked on it or anything like that.’</td>
</tr>
<tr>
<td>Emotion</td>
<td>‘I think it’s mostly because I had a really, really bad attitude.’</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expectation/Hope</td>
<td>‘... when I get angry, make me not like want to hurt my little sister cause she just gets on my nerves.’</td>
<td>[positive] ‘At first my parents told me to, but once I see that that actually help, I take it.’</td>
<td></td>
</tr>
<tr>
<td>Self</td>
<td>‘I’m a mental case.’</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavior/Action</td>
<td>‘... because I was having problems, real problems in school.’</td>
<td>‘It’s making me act better.’ [positive] ‘It’s my sleeping pill.’</td>
<td></td>
</tr>
<tr>
<td>Intersubjective</td>
<td>‘... they thought that I was disrespecting them if I told them no.’</td>
<td>‘I gain a relationship with my family again.’ [negative] ‘Oh D, you can’t behave? Oh D, you’re bad. You’re on medicine,’ cause kids in my school, they’ll make fun of you.’</td>
<td></td>
</tr>
<tr>
<td>Cognition/Thought</td>
<td>‘... when I wasn’t paying attention in school.’</td>
<td>‘... listening and focusing and stuff.’ [positive] ‘I think it actually helps me to focus and I think that anger is more like in my own hands.’</td>
<td></td>
</tr>
<tr>
<td>Body</td>
<td>‘... like headaches and stomachache’</td>
<td>‘It’s supposed to like balance out something in your brain.’ [negative] ‘I don’t want to take it trying to help something else and then it messes up another thing.’</td>
<td></td>
</tr>
<tr>
<td>Management</td>
<td></td>
<td>[negative] ‘That I’m going to get like five medicines at a time to take four times a day.’</td>
<td></td>
</tr>
</tbody>
</table>

**Notes:**
\(^1\) Assigned by sorting in-vivo codes and quotations into a common category.
\(^2\) Coders read adolescent responses or quotations and assigned them a positive or negative code based upon the adolescents’ positive or negative attitude toward the medication. See examples in this table.
Some adolescents understood their need for help and the need for medication as 'getting into trouble,' as 'swings in moods,' as problems in 'concentrating,' and as problems 'getting along with parents.' Others, by saying, 'I am ADD,' or 'I am bipolar,' viewed their need for help as self-defining, while others externalized the diagnosis, saying, 'I have an illness,' or 'I have depression,' or 'it applied to me.'

**How Medication Works**

Adolescent responses to queries about how medications work resulted in the creation of 87 in-vivo codes (linked to 441 quotations). These codes, representing how medications work, were contrasted and sorted, resulting in the identification of six themes: (i) body – how medication affected the body; (ii) emotion – how medication affected feelings and mood; (iii) cognition/thought – how medication affected thinking; (iv) behavior/action – how medication improved schoolwork or decreased aggression; (v) intersubjective – how medication improved relationships with mother, peers, and teachers; and, (vi) expectation/hope – what they wished medications would do for them. Column 2 of Table 2 offers examples of adolescent responses.

In general, adolescents reported that medication helped with sleep, 'to act right,' and 'do stuff better,' representing a belief that medication produced behavioral change. They described how parents and others influenced their experience and understanding of illness and medication; with this grouping of codes, we identified an intersubjective theme. For example, respondents (7 of 20) said that they learned from psychiatrists, mothers, television, internet, books, movies, and advertisements about how medications worked and what they affected. Among the intersubjective themes one was especially common (13 of 20): medications improved relationships at home, school, or with peers. Emotionally, medications were described as: 'it stabilizes,' 'it levels me,' 'it evens my moods,' 'it calms me down,' and 'it makes me proud of myself.' Adolescents hoped medications would do many things: provide a cure; control their anger. They hoped medications would not stop working, or that they would relieve family stress. They hoped for an easier regimen (e.g., a once a day drink, or patch instead of pills).

**Side Effects**

Adolescent experience with medication side effects was linked to 27 in-vivo codes. Comparison of the shared characteristics of the quotations linked to side effect codes produced two themes: (i) body – how treatment resulted in unwanted physical concerns and; (ii) emotion – how treatment resulted in unwanted feelings. Answers commonly associated with
physical/bodily themes were: sleepiness, stomachache/heartburn, headache, hand tremors, dizziness, reduced appetite, interference with taste, weight gain, and blurred vision. Other quotations were linked to codes that were grouped under an emotional theme: worries about being too happy or hyper, worries about becoming dependent on the medication, worries about feeling high, and worry that the medications made them 'act differently.' Only 3 of the 20 reported minimal or no side effects.

**Perceptions of Adherence**

Forty-eight in-vivo codes (linked to 180 quotations) referenced adherence experience; these were compared and grouped under seven themes: (i) expectation/hope – how medication had either disappointed or produced the desired effect; (ii) intersubjective – how relationships had improved; (iii) emotion – how feelings had improved or not; (iv) body – negative or positive physical concerns; (v) management – the tedious nature of daily management; (vi) cognition/thought – negative or positive; and, (vii) behavior/action – better grades and fewer behavioral problems (see Column 3 of Table 2 for examples). Although more adherence experiences were coded as negative (30 of 48 negative), positive feelings were frequently (18 of 48 positive) reported. Negative experience with medication was described as; bodily side effects, difficulties remembering to take medication and worries about dependency. Positive feeling, on the other hand, was linked to improvements in the quality of family, peer, and school relationships, emotional stability, and feeling that medication worked as hoped.

In summary, themes that emerged suggest that adolescents refer to their bodies, emotions, behavior, thoughts, self, and expectation/hope when making sense of medication treatment. It also appears that perceptions of medication are drawn heavily from parents and doctors; however, peers, siblings, counselors, Internet, television, and movies were also identified and could be significant interpersonal influences upon overall experience.

**Case Illustration**

Alicia, a 14-year-old Caucasian female in a regular eighth grade classroom (on an Individual Education Plan), was prescribed an antidepressant at age twelve and at the time of the interview was taking an antipsychotic and a mood stabilizer. The K-SADS diagnostic interview suggested a group of Bipolar 1 symptoms, euthymic, with rapid cycling. The diagnostic interview also suggested secondary diagnoses of ADHD-combined type, separation anxiety, oppositional defiant disorder, and conduct disorder. Alicia and her mother reported adherence to the medication regimen 'all of the time.' And her Clinical Global Assessment score was near the
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mid-range, suggesting that at school, with peers and family, she had normal functioning with only occasional problems.

In response to TeenSEMI questions about the need for treatment (e.g., can you tell me in your own words, why you see the psychiatrist?), Alicia reported:

I think the reason why I’m going is because I have bipolar. I felt like I was doing fine, but I guess there were kind of different things going on. (coded Diagnosis/Disorder/Symptom)

I think it’s mostly because I had a really, really bad attitude and if I didn’t like what they [parents] said, I didn’t want to hear it, and if I didn’t like it and they kept telling me, I’d start screaming, so they knew something was wrong with me. (coded Emotion)

Because when I have a bad episode, I tend to black out, I don’t remember things . . . like these glasses. I took them when I was mad and I twisted them all up and . . . I don’t remember doing it at all. My mom just told me. (double coded, Body and Behavior)

Like I would have outbursts every single day. (coded Emotion)

[what do you think caused you to have these concerns?] I’m not sure if this is really it, but the move [referring to moving out of grandma’s house after her death], because that just made my emotions go absolutely crazy. I mean I’ve lived in that house my whole life up to the 4th grade . . . That was my grandma’s house before she died, I mean, and I met my best friend at that house, and it just kind of felt like, oh my god. Look I’m just totally leaving, and it just made me really upset and made my emotions go crazy. (coded Emotion)

Well that’s when [six months after seeing a psychiatrist the first time] I first started to hear, they started saying bipolar, but also, I just remember two months into that, they had me ODD [oppositional defiant disorder], separation anxiety, and mania. (coded Diagnosis/Disorder/Symptom)

He [psychiatrist] kind of told my mom, before he told me, and then my mom sat down and explained it to me and we went and got some books from the library and we pretty much just read up on them and seen what they really were. (coded Intersubjective)

My best friend’s twin brother . . . we became really good friends . . . we [her friend] would always make jokes about him and laugh at him because he was bipolar . . . and he kind of explained to me what it was and how you have to just deal with it. (coded Intersubjective)

At first I was like, ‘no I can’t be bipolar.’ That’s just not me. I don’t want to be it and then when I started actually seeing what was really going on, I’m just like, oh my god, I can’t believe I just said that I wasn’t this, and now I am. (doubled coded Diagnosis/Disorder/Symptom and Self)
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[so will the diagnosis of bipolar go away, do you think, over time?] No ... its there to stay. (double coded Diagnosis/Disorder/Symptom and Self)

I only thought it was people like really crazy, and you know like the hobo thing you see on the street singing to themselves and just walking back and forth, that's what I thought they were. Really all of it. Like I was able to relate to every single part of it. (coded Self)

I also still have separation anxiety. [and where did you get that name?] The CLINIC. I got that from The CLINIC, who told my mom, then my mom told me ... She explained it to me ... I didn't realize like what separation anxiety is, and then she's just all like, 'well do you remember when grandma died?' And I go, 'yeah.' 'Do you remember how you won't let that go and you probably will never let that go?' I'm like 'Yeah ... that is what separation anxiety is.' [and that again felt true to you?] yeah. (double coded, Self and Diagnosis/Disorder/Symptom)

In response to questions about how medications work, Alicia offered the following:

I started taking medicine and I would see a total different person when I took the medicine. I mean I wasn't so angry and I was able to have a good time and laugh and just have fun. (triple coded Emotion, Self, and Intersubjective)

[what went through your mind when medication was first suggested?] I felt like they thought I was crazy. (coded Self)

[do you recall what that first medication was called?] Oh I can't remember it. I know it's always on TV with the little happy dot thing. [how did that feel to you when you saw something on TV that you were taking?] I just made fun of it a lot, like me and my mom. Like if I didn't feel like taking it, my mom was like, 'go take your happy dot pill.' (coded Intersubjective)

[if a medication could do anything you wanted for the concerns you have mentioned, what would you wish it could do for you?] Nothing for me, mostly for my family. I feel that way so they won't have to go through all the pain that they had to go through (coded Intersubjective)

[what do you think the (antipsychotic) actually does for you?] It's my sleeping pill ... I take it and I kind of get all goofy for like an hour, and then I'll be really, really hungry and I'll eat all these calories, then I'll go to bed. [so you couldn't sleep before the antipsychotic?] I could, just not as well. Like if I heard my dog walking pass my bedroom, I'd wake up and didn't know what to do, and I'd lie there for like two hours trying to go back to sleep, because I can't fall asleep without my TV on. So I'd turn on my TV and just lie there, watch TV and not be able to go back to sleep. [so the antipsychotic helps you sleep all through the night?] yeah. (coded Behavior)
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[what do you think the (mood stabilizer) actually does for you?] It balances off all my . . . mood swings to where I won’t have as many. It’s like with my brother, he’ll get me mad, and before [medication] I would just straight up and hit him . . . I don’t get as aggravated . . . I mean when I was off the medicine, I would kind of like always get into trouble for aggression. I got in a fight at school. I got suspended. I got put in the court system. I beat another girl up outside of school. (coded Behavior and Emotion)

[what are some things that medication can’t do for you?] Right now I’m loving life. I have great friends. I mean there’s nothing better that I can ask for right now. It can’t just totally keep me happy all the time. It’s just the part that everybody has . . . it is normal to get a little annoyed . . . I mean it [medication] controls it [aggression] but it does not take all of it away.’ (coded Emotion and Intersubjective)

[what do you think your mother or father want medication to do for you?] Right now my mom likes the medication on me. I mean she even said she couldn’t ask for anything better . . . My dad, honestly, doesn’t want me on medication, because when he was younger, he was on medication. It didn’t work for him. But my mom said that it works, and he said that he’s starting to know a difference, but he’s still kind of like, ‘well I still don’t want her on medication.’ (coded Intersubjective)

[how long do you think others believe you should take your current medication?] I don’t want to take them all, but it’s something I have to do . . . the rest of my life . . . They told me I’m going to be bipolar for the rest of my life and I’m going to be stuck on medication. [who is they?] My mom, dad, my doctor, my psychiatrist, my counselor, my teachers, my [school] principal. (coded Intersubjective)

[some people believe that we should not take medication and fix ourselves, what do you think about that?] I thought the same way. I mean it’s kind of like I was getting brainwashed by one of my friends, and she was like, ‘by 2010 almost everybody in the world’s going to be on medicine,’ and then I started to see the real truth, and it’s just I feel like why would they put me on it if it really didn’t work? I mean are they trying to fool me or get my insurance money or something? But then I really found out. (coded Intersubjective)

How are we to understand the clinical/diagnostic and psychosocial referents in Alicia’s narrative? First, while she was ‘given’ diagnoses for bipolar and separation anxiety, clinicians turned to her mother to offer explanatory accounts: ‘He [psychiatrist] kind of told my mom, before he told me, and then my mom sat down and explained it to me.’ And while Alicia internalized an illness/disorder identity – I am bipolar (‘now I am’) – she also produced a distance between herself and the diagnosis by stating that the diagnosis (‘it’) had been given to her (‘they started saying’; ‘they had me’). Moreover, while bipolar was something she had ‘for life,’
assigned to her by clinics and psychiatrists, she also saw a possible connection to the death of her grandmother and the move from her grandmother’s house. She said, ‘it just made my emotions go absolutely crazy.’ And while she thought medication worked on her aggression, it seemed also to leave some part of it unaddressed.

Alicia wondered whether her friend was correct to think that by 2010 everybody in the world would be on medication? She seemed to be saying: ‘if everybody is on medication, and I am on medication, then I am like everyone.’ This was, however, more than a simple normalization of experience. It is in this complex, intersubjective dynamic that Alicia joined others to co-produce the meaning of the medication experience. Indeed, this intersubjective dynamic is to be found in all 20 interviews. The clinical implications, we believe, are far-reaching. Psychiatrists, for example, must attend not only to prescribing the antidepressant, they must grasp how Alicia, and her mother make sense of the ‘happy dot pill.’ The television advertisement referred to in the narrative above suggests that medication targets neurotransmitters and depressive/behavioral symptoms; but mother and daughter are equally influenced by the drug’s implied power to create happiness. Alicia and mother found humor in the commercial by joking about the tedious nature of daily medication management. Of the intersubjective influences on medication experience perhaps most significant was Alicia’s belief that taking medication both pleased her mother and resulted in fewer fights with her brother. Alicia’s motivation to adhere to the medication was related in part to her perception that it helped make peace in the family. This finding suggests that medicating adolescents is symbolically medicating a family because the effects of medication generate meanings that implicate an entire family system (Chubinsky & Rappaport, 2006; Oldani, 2009; Rappaport & Chubinsky, 2000).

**Discussion**

Alicia’s medication experience presents several possibilities for further inquiry. Peter Conrad (2007), for example, has recently looked at how social and psychological problems are increasingly framed by and acted upon through biomedical assumptions. Drawing on such work, one might explore the relationship between medicalization and psychiatric medications by examining how Alicia simultaneously adopts and accepts both the bipolar diagnosis and psychosocial explanations of her difficulties. For example, we might ask how psychiatric medicalization produces fundamentally new possibilities for conceptions of self, as determined by the medication experience. Moreover, asking such questions can highlight the analytical limitations of concepts such as medicalization and the globalization of pharmaceuticals. Thus while one can easily join Alicia in
imagining a world in which everyone is on psychiatric medications, globalization, like medicalization, is a not a sufficiently rich concept to provide an adequate account of how individuals ultimately make sense of their medication experiences. These concepts, for example, would not help us conceptualize how for Alicia the ubiquity of medication becomes a potential defensive projection aimed at normalizing stigma or shame about her illness or medication experience. David Karp shows in his work with teenagers how anti-depressants in schools produced an intersubjective experience of stigma (Karp, 2006). Whichever direction the cause and effect might run in these instances, there is little doubt that for Alicia the hoped-for symptom-focused biomedical model is just one of many ways in which she makes meaning of psychiatric medications.

Over the set of 20 adolescent respondents, personal and interpersonal themes of adolescent psychotropic treatment might be understood as different points of view through which adolescents understand and take action related to: their illness concerns; their need for medication treatment; their perceptions of how medications work; their responses to parental and other influences upon medication treatment; and their everyday management activities. The theme of expectation and hope seems particularly central to their experience. It is in the space between the successful and disappointing medication treatment that adolescents wonder: ‘why take medications,’ ‘what will they do for me,’ ‘will they harm me,’ and ‘how will I manage them.’ Our findings suggest that adolescents will deploy one or several personal and interpersonal life domain dimensions to answer these questions and in doing so make psychotropic treatment meaningful.

As is the case with all of those interviewed for this study, Alicia’s particular diagnosis and medication experience is mediated by complex social dynamics. Observation and interpretation of adolescent medication effects are shaped by family, community, cultural, and personal belief and attitude toward: the diagnosed illness; how diagnoses are made; and the treatment, including the nature of the relationship between practitioner and treatment recipient. Our model for representing adolescent medication experience and management is summarized in Figure 1. The model is comprised of five elements of a medication experience, represented vertically (highlighted in gray) as the socio-cultural dimension: (i) problem, (ii) prescription assessment, (iii) access and payment, (iv) monitoring and interpreting effects, and (v) reporting effects. Furthermore, pharmaceutical interests, insurance/payment policies, and the organization of local mental health services set the parameters for the medication experience. For example, the local service provider may be resource depleted or influenced by a single or reductionist model of the relationship between mind and body. Horizontally we have depicted the
<table>
<thead>
<tr>
<th>Socio-cultural Dimension</th>
<th>Personal Intersubjective Dimension</th>
<th>Social Relations of Medication Management</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Problem and diagnosis</td>
<td>Subjective Emotion</td>
<td>Intersubjective Parent, Peer, Teacher, Clinician expectations</td>
</tr>
<tr>
<td></td>
<td>Subjective Cognition</td>
<td>Beliefs and attitudes about the illness and diagnosis</td>
</tr>
<tr>
<td></td>
<td>Subjective Body</td>
<td>How is the body indexed to a diagnosis?</td>
</tr>
<tr>
<td></td>
<td>Subjective Intersubjective Parent, Peer, Teacher, Clinician expectations</td>
<td>How is the body indexed to a desired effect?</td>
</tr>
<tr>
<td></td>
<td>Subjective Beliefs and attitudes about medication producing the desired effect!</td>
<td>Beliefs and attitudes about paying and service access?</td>
</tr>
<tr>
<td></td>
<td>Subjective What are the feelings, thoughts, and beliefs about compliance, monitoring, and the actual effects of medication?</td>
<td>Among all involved, who reports medication effects to whom?</td>
</tr>
<tr>
<td>(2) Medication prescription and clinically hoped-for effects</td>
<td>Subjective What emotions get indexed to desired effects?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Subjective Beliefs and attitudes get indexed to desired effects?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intersubjective How is the body indexed to a desired effect?</td>
<td></td>
</tr>
<tr>
<td>(3) Access and payment</td>
<td>Subjective What emotions get indexed to paying and service access?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Subjective Beliefs and attitudes get indexed to paying and service access?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intersubjective How is the body indexed to paying and service access?</td>
<td></td>
</tr>
<tr>
<td>(4) Monitoring adherence and interpreting gap between hoped for and actual effects, including unintended side effects</td>
<td>Subjective What emotions can be indexed to compliance, expected, and actual effects?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Subjective Beliefs and attitudes can be indexed to compliance, expected, and actual effects?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intersubjective How is the body indexed to compliance, expected, and actual effects?</td>
<td></td>
</tr>
<tr>
<td>(5) Reporting effects, including unintended side effects</td>
<td>Subjective How are medication effects on emotions reported?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Subjective Beliefs and attitudes about effects are reported?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intersubjective Among all involved, who reports medication effects to whom?</td>
<td></td>
</tr>
</tbody>
</table>

**Figure 1** Socio-cultural, personal, and interpersonal matrix of adolescent medication experience and management.
subjective (i.e., personal) and intersubjective (i.e., interpersonal) dimensions of the adolescent psychopharmaceutical experience.

The subjective aspect of medication treatment has two dimensions and addresses the degree and nature of involvement, passive or active (Longhofer, Floersch, & Jenkins, 2003b), in making sense of the biopsychosocial domains; Alicia, for example, was actively engaged in making a psychosocial claim about her illness: she wondered about the effect of her grandmother's death on her intense affect. And while one might see this as active resistance to the biological diagnosis, Alicia just as actively embraced her bipolar diagnosis: she engaged with her mother to determine the cause of her affective storms. Moreover, she reported that medication reduced aggression and also linked the medication's effect to an acceptance of the correct diagnosis, '... it balances off all my ... mood swings to where I won't have as many.' Alicia's references to the biopsychosocial domains of emotion, cognition, and body show us the personal and interpersonal dynamic of her medication experience and the sociocultural milieu organizing her experiences around DSM-IV categories and medication treatment. The aggregate data and case illustration remind us of the danger of reducing our assessment of medication treatment to its biological or clinical effects; assessment must include attention to extra-clinical, sociocultural effects.

The intersubjective dimension also refers to how passively or actively the adolescent engages others, (i.e., parents, peers, teachers, clinicians, and friends) the Internet, popular magazines or culture, and libraries in gathering information that shape how they make sense of the psychotropic experience. Alicia, for example, was influenced by the Zoloft commercial, as well as by a peer's brother who had been diagnosed with bipolar disorder. She also took medication, in part, to please her mother. At the same time, her father remained skeptical of the pharmacological treatment. Indeed many adolescents in this study reported that fathers were not engaged in treatment decisions, and were similarly ambivalent. The influence of skeptical fathers on their children presents a challenge: when parents disagree over medication use, how does this affect the medication experience?5

The system of medical, clinical diagnosis produces a particular intersubjective field for making meaning of everyday medication experience. And while it might be easy for some to imagine that psychiatric diagnoses are made based solely on 'detecting signs that point to objective, measurable parameters' (Verhaeghe, 2004, pp. 17-18) in practice psychodiagnostics always requires interpretation. Although at the time of Alicia's interview bipolar disorder was the principal diagnosis, she had been given several diagnoses over the years. Clinicians prescribing medications are obligated to connect the suggested use and type of drug
(e.g., anti-psychotic, mood stabilizer, psychostimulant, etc.) to particular diagnoses. Yet, these data suggest that it does not necessarily follow that the recipient accepts the diagnosis and the connection between a specific disease/disorder and its associated medication. Diagnosing youth, moreover, presents serious challenges. Alicia’s history of multiple diagnoses illustrates this challenge and raises the question: which diagnosis did she identify with and why?

Table 3 compares the self-reported diagnosis of the 20 participants with that of the K-SADS-PL. The comparison shows that 13 of 20 adolescents did not report a disjuncture between their diagnostic understanding and the K-SADS-PL, a standard symptom-based assessment. For 7 (highlighted in gray), however, there was a disjuncture, raising questions about how they experienced the gap between the clinician’s diagnostic interpretations and their own understandings of the problem and associated medication treatment.

**Conclusion**

For most people who take aspirin for headaches, the hoped-for effect is credited to the power of the drug. Between the expected (hoped-for or desired) and the experienced effects of medication, there exists a phenomenological, subjective and intersubjective gap (Longhofer & Floersch, 2004; Longhofer, Floersch, & Jenkins, 2003a). When medicine is believed to be the agent that delivers the expected effect, the gap between desired and experienced effects is narrowed. In such cases, patients are likely to interpret treatment effects as tangible and focused. On the other hand, this gap between expectations and experience may be quite large when the anticipated effects of a medication are less well defined and when others assert their expectations (Floersch, 2002). Thus, in relation to reducing or eliminating psychiatric symptoms like depression, anxiety, and irritability, the expected effects may be elusive, transient, or difficult to pinpoint. In the present study, Alicia, for example, regarded the medication’s role in reducing aggression in positive terms; yet she also recognized, ‘it doesn’t take it all away.’ She seemed to be asking: how much aggression is normal? Or: how much is left over after the medication takes care of its portion? There was another gap between her expectation that the medication will help her and that it would help others: ‘Nothing for me, mostly for my family.’ This gap represents a subjective and intersubjective space within which the medication recipient (or others in their network) observes, monitors, and interprets. Meanwhile, adolescents’ interpretations of medication effects are always embedded in the broader context of sociocultural factors related to mental health services and biopsychiatry.
### Table 3
Participant self-report diagnosis compared with research, KSADS-PL diagnosis

<table>
<thead>
<tr>
<th>N = 20</th>
<th>Self-Report Diagnosis</th>
<th>Primary KSADS-PL Diagnosis</th>
<th>Second KSADS-PL Diagnosis</th>
<th>Third KSADS-PL Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Bipolar</td>
<td>Bipolar</td>
<td>ADHD</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Seizures, does not know</td>
<td>Schizophrenia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Bipolar</td>
<td>Bipolar</td>
<td>Separation Anxiety</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>ADD</td>
<td>ADHD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Bipolar, ODD, Anxiety</td>
<td>Bipolar</td>
<td>Conduct Disorder</td>
<td>ODD</td>
</tr>
<tr>
<td>6</td>
<td>Depression</td>
<td>Major Depressive Disorder</td>
<td>PTSD</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Bipolar, ADD, Depression</td>
<td>Bipolar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>ADHD, ODD</td>
<td>Bipolar</td>
<td>ADHD</td>
<td>ODD</td>
</tr>
<tr>
<td>9</td>
<td>Depression, Bipolar</td>
<td>Major Depressive Disorder</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Bipolar</td>
<td>Bipolar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>ADHD, Depression</td>
<td>Major Depressive Disorder</td>
<td>ADHD</td>
<td>Panic Disorder</td>
</tr>
<tr>
<td>12</td>
<td>Mood Disorder</td>
<td>Bipolar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Depression, Eating Disorder</td>
<td>Major Depressive Disorder</td>
<td>Eating Disorder</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Bipolar, ADHD, Depression, Anxiety</td>
<td>Substance Induced Mood Disorder</td>
<td>ADHD</td>
<td>ODD</td>
</tr>
<tr>
<td>15</td>
<td>ADHD</td>
<td>Bipolar</td>
<td>ADHD</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Forgot – does not know</td>
<td>Eating Disorder</td>
<td>Avoidant D/O</td>
<td>Enuresis</td>
</tr>
<tr>
<td>17</td>
<td>ADD</td>
<td>Major Depressive Disorder</td>
<td>ADHD</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Did not give a name</td>
<td>ADHD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Depression, ADD</td>
<td>Bipolar</td>
<td>ADHD</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>ADD</td>
<td>ADHD</td>
<td>Enuresis</td>
<td></td>
</tr>
</tbody>
</table>
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NOTES

1. This outpatient research protocol was reviewed and approved by the University of Hospitals Case Medical Center Institutional Review Board for Human Investigation. The parents/guardians of the research participants provided written informed consent and all adolescents provided written informed assent prior to study participation. The interviews conducted under the auspices of this study took approximately six hours. Parents received $50 and adolescents $65, respectively as honoraria.

2. Prior to administering the diagnostic assessment, the rater met adequate inter-rater reliability standards (kappa > .85) on five consecutive interviews while observing a trainer-rater and on five consecutive interviews while leading the interview; a rater’s kappa of ≥ 85 indicates that eighty-five out of hundred conclusions would reliably match other raters trained with the same protocol.

3. The type of coding procedure used in this analysis is a synthesis of the following grounded theory approaches: Boeije, 2002; Charmaz, 1990, 2006; Glaser & Strauss, 1967; Muhr, 1993; Sivesind, 1999.

4. Indirect support for these findings includes research that has emphasized that adult experience is mediated by culture, mental health systems, and medicalization processes (Conrad, 2007; Floersch, 2002; Jenkins et al., 2005; Karp, 2006; Kirmayer, Young, & Robbins, 1994; Kleinman 1988).

5. Results from one clinical drug trial have noted that a medication’s intended effect was moderated by the degree of family conflict (see Townsend, Demeter, Youngstrom, Drotar, & Findling, 2007).

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Adolescent Experience of Psychotropic Treatment

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Abstract  Despite growing concern over the treatment of adolescents with psychiatric medications, little research has examined youth understandings and interpretations of mental illness and psychotropic treatment. This article reports the exploratory findings of semi-structured and open-ended interviews carried out with 20 adolescents diagnosed with one or more psychiatric disorders, and who were currently prescribed psychiatric medications. Grounded theory coding procedures were used to identify
themes related to adolescent subjective experience with psychiatric medications. The categories identified are interpreted as different points of view through which adolescents understand and take action upon their illness concerns; their need for medication treatment; their perceptions of how medications work; their responses to parental and other influences upon medication treatment; and, their everyday management activities.

**Key words**  adolescent • medication management • psychiatric medication • qualitative research • subjective experience,

**INTRODUCTION**

Concern regarding adolescent mental health treatment with psychiatric medication has intensified among researchers, families, and practitioner groups, as the rate at which youth are prescribed psychotropic agents has increased over the last 20 years (Cooper et al., 2006; Olsson, Marcus, Weissman, & Jensen, 2002; Thomas, Conrad, Casler, & Goodman, 2006; Wong, Murray, Camilleri-Novak, & Stephens, 2004; Zito et al., 2003). Given this increasing use, researchers have called for studies of safety and efficacy because, it is argued, youths may respond to psychiatric medications differently than adults (Findling & Wiznitzer, 2003). Yet despite increasing scientific investigation into the effectiveness and tolerability of psychotropic agents in young people, there are limited data on how adolescents prescribed psychotropic agents subjectively experience medication treatment. We should not assume that youth have understood their illness, made sense of their medication treatment, and have adhered to a regimen as have adults. Indeed, social scientists have emphasized the many ways, active and passive, in which adults understand mental illness, diagnosis, medication treatment, and adherence (Charmaz, 1990; Conrad, 1985; Jenkins, 1994; Karp, 1996; Kleinman, 1988). Among adults with major depression, for example, David Karp (1996, p. 102) concluded that, ‘... the experience of taking antidepressant medications involves a complex and emotionally charged interpretive process in which nothing less than one’s view of self is at stake.’ Understanding the interpretive or psychosocial aspect of youth psychotropic treatment, as Karp has argued for adults, may improve youth medication treatment. Thus, while the knowledge gap about the safety and efficacy of youth psychotropic treatment is gradually being addressed, we must now turn our attention to how youth make the treatment experience meaningful (Floersch, 2003).

Health research has demonstrated that adolescents draw upon personal perceptions, beliefs, and meanings in their experience of medical interventions. For example, adolescents modify medical advice about asthma when they believe that their knowledge of physical events supersedes the knowledge of doctors (Buston & Wood, 1999; Jessop & Rutter, 2003).
Others report that adolescents discontinue asthma medication when they are unaware of specific bodily symptoms such as dyspnea (van Es et al., 1998). It has been shown that adolescents with chronic asthma stopped medication when they thought it was ineffective, or when believed they did not have the illness (Buston & Wood, 1999; van Es et al., 1998). Research on diabetic and asthma patients has found that adolescents may also assert autonomy by resisting standard treatment (Adams, Pill, & Jones, 1997; Kynagas & Hentinen, 1995) and may not adhere to prescribed treatments when they do not feel like taking medication (Hanna & Guthrie, 2000; van Es et al., 1998). Similarly, HIV-positive adolescents report how they avoid antiretroviral regimens when they feel healthy (Pugatch, Bennett, & Patterson, 2002). Cromer and Tarnowski (1989) show how adolescents treated for general medical conditions stop medications that prevent illness progression or episodic exacerbations when interventions lack the behavioral reinforcement of immediate relief from physical symptoms. In short, the literature on illness beliefs in medicine suggests that adolescents respond to medication treatment in profoundly personal ways that influence adherence and treatment effectiveness.

In this article, we report qualitative findings from a larger mixed-method study of adolescent psychotropic experience. Our aim here is to use grounded theory coding procedures to identify thematic categories adolescents use in making meaningful the psychotropic experience, specifically: (1) how do adolescents internally represent illness concerns and need for medication treatment?; (2) how do adolescents think medications work?; and, (3) how do adolescents perceive their participation in routine medication management activities?

**Method**

**Sample**

Subjects were recruited through discussions with professional staff, and fliers and posters aimed at patients seen within the outpatient clinic in the Division of Child and Adolescent Psychiatry at a university hospital, community mental health outpatient settings, and an alternative high school for adolescents with emotional and behavioral problems. Only adolescents, ages 12 to 17, meeting DSM-IV criteria for a psychiatric illness and currently being prescribed a psychotropic medication were eligible. Participants were excluded when parents reported that the adolescent had not taken psychiatric medication at least once in the past 30 days. Moreover, adolescents with developmental disability (i.e., IQ lower than 70), a pervasive developmental disorder, seizure disorder, or an organic brain disorder, were not enrolled.1
Measures

Interviews for this study were carried out using the Teen Subjective Experience of Medication Interview (TeenSEMI), a semi-structured interview instrument, adapted from the adult version. The adult SEMI was designed to obtain narrative data about medication treatment from those diagnosed with schizophrenia (Jenkins, 1997; Jenkins et al., 2005). The TeenSEMI was produced by eliminating or modifying questions for adults (e.g., questions about work, marriage, and recovery) and developing age-relevant questions (e.g., questions about school, peer, and family interactions). The final interview schedule, approximately 150 questions, included 9 categories related to illness, treatment, and medication: (i) treatment, illness, and medication history; (ii) perceptions of medication; (iii) managing, monitoring, reporting of medication experience; (iv) parent and adolescent interaction regarding medication management; (v) illness and medication stigma; (vi) adolescent and school interactions regarding medication management; (vii) adolescent and peer interactions regarding medication management; (viii) access to mental health services regarding medication experience; and, (ix) ethnicity, gender, and religious influences regarding medication experience.

In addition to data produced with the semi-structured instrument, we collected adolescent and family demographics and psychiatric/medication treatment history. The Kiddie Schedule for Affective Disorders for School-Age Children Present and Lifetime Version (K-SADS-PL) (Kaufman et al., 1997) was used to determine participant diagnoses and the Child Global Assessment Scale (Shaffer et al., 1983) was used to assess overall functioning at home, with peers, and in school. The K-SADS-PL, a semi-structured research interview, has been used as a 'gold' standard to assign diagnostic categories in clinical drug trials or psychosocial intervention studies. It assesses symptom constellations according to DSM-IV psychiatric diagnoses in pediatric patients based on information provided by youth and parents or caregivers. The K-SADS-PL diagnostic interviews were conducted by a researcher (second author) trained as a 'rater' to administer the instrument.2 The use of the K-SADS-PL does not resolve the many issues related to diagnostic validity because symptom-based diagnostic systems are known to be culturally and historically sensitive (Horwitz & Wakefield, 2007; Kirk & Kutchins, 1992). For example, controversy exists over whether or not bipolar illnesses are accurately applied to youth (Moreno et al., 2007; Smith, 2007). In our research, the use of the K-SADS-PL meant that the researcher/rater followed the protocols for symptom-based diagnosis and when the outcome was bipolar, for example, trained raters (with a kappa ≥ 85) would have agreed with the diagnosis 85% of the time.
DATA ANALYSIS

In analyzing the data we assigned in-vivo code names using the actual words of the adolescent; the in-vivo codes were grouped by themes that emerged from comparing their shared characteristics. The specific grounded theory coding steps we utilized consisted of: (i) focused coding, which assigned in vivo codes that reflected data content; (ii) constant comparison of the focused codes, subsequently sorted by similar themes; and, (iii) axial coding, connecting the findings from steps one and two by sorting the discovered themes under broader umbrella categories and specifying how they relate to one another.3

This coding exercise resulted in sorting adolescent experience according to the following umbrella themes: (i) illness, disease, clinical symptoms, or clinical diagnosis; (ii) feelings or emotions; (iii) some aspect of the self; (iv) behavior; (v) relationships; (vi) cognition; (vii) physical concerns; (viii) expectations or hopes for what medications would do; and, (ix) medication management activities. In the final analytic step these themes were sorted according to the three research questions: illness and treatment perceptions about how medications work; and medication management perceptions.

Coding reliability was established by a process of seven coders independently coding 6 adolescent interviews; this combined effort generated nearly 500 in-vivo codes (themes based on concepts used by the interviewees). Then, the first author and study principal investigator (PI) examined the codes to eliminate redundancy. For example, when the same quotation was given different code names, they were reassigned to a single code. This process eliminated nearly 289 redundant codes, resulting in a ‘master codebook’ of 211 codes based on the first 6 interviews. This master codebook was then used by the coders for the remaining 14 interviews. Coders were instructed to create new codes from the 14 subsequent interviews only if codes in the master codebook failed to fit the new data; the PI then reviewed the code list generated from the 14 interviews and added new codes to the master list. The PI conducted a validity assessment of the final data set by checking that: (i) the codes referring to quotations were consistently applied across all 20 interviews; (ii) codes were appropriately grouped under the thematic categories; and, (iii) themes were appropriately grouped under the three research questions.

RESULTS

PARTICIPANT DEMOGRAPHICS AND CLINICAL PROFILE

Twenty youths participated in this study. The mean age was 14.75 years (SD 1.6); 9 were male and 11 female, 8 African American and 12
Euro-American; the mean years of education was 8.85 (SD 1.63). The mean number of prescribed psychotropic medications was 2.35 (SD 1.09) and average age at first prescription 10.35 years (SD 3.01; range 5–15 years). The mean number of prior hospitalizations was 3.4 (SD 2.3, range 0 to 9 times) and the age at first hospitalization 12.78 (SD 1.99).

There was a high rate of psychiatric comorbidity with subjects meeting diagnostic symptom criteria for an average of 2.35 (SD. 1.53) psychiatric diagnoses (see Table 1 for summary of psychiatric diagnoses).

The average CGAS (Clinical Global Assessment Scale) score at enrollment was 61.40 (SD 11.83), suggesting 'variable functioning with sporadic difficulties.' At the time of enrollment, parents (n = 20) reported adherence 'all the time' (n = 13), 'usually' (n = 6), and 'sometimes' (n = 1). Adolescents (n = 20) self-reported adherence 'all the time' (n = 18) and 'sometimes' (n = 2).

**Adolescent Experience of Psychotropic Treatment**

**Illness and Medication Treatment Experience**

The TeenSEMI questions that elicited adolescent experiences of mental illness and treatment generated 74 in-vivo codes (linked to 273 quotations). These were compared and sorted to produce seven emergent themes: (i) emotion – references to emotional problems; (ii) diagnosis/disorder/symptom – reference to psychiatric illness, disease, or diagnosis; (iii) self – reference to some aspect of the self as the problem; (iv) cognition/thought – reference to cognitive problems; (v) intersubjective – reference to relationship problems; (vi) body – reference to physical problems, and; (vii) behavior/action – reference to behavioral or school problems. Column 1 of Table 2 gives examples of the themes and related adolescent responses.

**TABLE 1**  
Diagnostic profiles of subjects (N = 20)

<table>
<thead>
<tr>
<th>K-SADS-PL DSM-IV Diagnosis</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mood disorder</td>
<td>15</td>
<td>75</td>
</tr>
<tr>
<td>ADHD</td>
<td>12</td>
<td>60</td>
</tr>
<tr>
<td>Disruptive behavioral disorder</td>
<td>7</td>
<td>35</td>
</tr>
<tr>
<td>Substance abuse disorder</td>
<td>2</td>
<td>10</td>
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<td>Anxiety disorder</td>
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<td>10</td>
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<tr>
<td>Eating disorder</td>
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<td>10</td>
</tr>
<tr>
<td>Panic disorder</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Psychotic disorder</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Other disorders</td>
<td>5</td>
<td>20</td>
</tr>
</tbody>
</table>

*Percentages sum to > 100 due to comorbidity
TABLE 2
Adolescent perceptions of medications – selected quotations

<table>
<thead>
<tr>
<th>Theme</th>
<th>Need for Medication Treatment</th>
<th>How Medications Work</th>
<th>Adherence to Medication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis/Disorder/Symptom</td>
<td>'it was for anxiety attacks and depression'</td>
<td>'They balance off my mood swings to where I won't have as many.'</td>
<td>[negative]² 'I don't want to get hooked on it or anything like that.'</td>
</tr>
<tr>
<td>Emotion</td>
<td>'I think it's mostly because I had a really, really bad attitude.'</td>
<td></td>
<td>'I don't want to get hooked on it or anything like that.'</td>
</tr>
<tr>
<td>Expectation/Hope</td>
<td>'... when I get angry, make me not like want to hurt my little sister cause she just gets on my nerves.'</td>
<td>[positive] 'At first my parents told me to, but once I see that that actually help, I take it.'</td>
<td></td>
</tr>
<tr>
<td>Self</td>
<td>'I'm a mental case.'</td>
<td>[positive] 'It's my sleeping pill.'</td>
<td></td>
</tr>
<tr>
<td>Behavior/Action</td>
<td>'... because I was having problems, real problems in school.'</td>
<td>'It's making me act better.'</td>
<td></td>
</tr>
<tr>
<td>Intersubjective</td>
<td>'... they thought that I was disrespecting them if I told them no.'</td>
<td>'I gain a relationship with my family again.'</td>
<td>[negative] 'Oh D, you can't behave? Oh D, you're bad. You're on medicine,' cause kids in my school, they'll make fun of you.'</td>
</tr>
<tr>
<td>Cognition/Thought</td>
<td>'... when I wasn't paying attention in school.'</td>
<td>'... listening and focusing and stuff.'</td>
<td>[positive] 'I think it actually helps me to focus and I think that anger is more like in my own hands.'</td>
</tr>
<tr>
<td>Body</td>
<td>'... like headaches and stomachache.'</td>
<td>'It's supposed to like balance out something in your brain.'</td>
<td>[negative] 'I don't want to take it trying to help something else and then it messes up another thing.'</td>
</tr>
<tr>
<td>Management</td>
<td></td>
<td></td>
<td>[negative] 'That I'm going to get like five medicines at a time to take four times a day.'</td>
</tr>
</tbody>
</table>

Notes:
1 Assigned by sorting in-vivo codes and quotations into a common category.
2 Coders read adolescent responses or quotations and assigned them a positive or negative code based upon the adolescents' positive or negative attitude toward the medication. See examples in this table.
Some adolescents understood their need for help and the need for medication as ‘getting into trouble,’ as ‘swings in moods,’ as problems in ‘concentrating,’ and as problems ‘getting along with parents.’ Others, by saying, ‘I am ADD,’ or ‘I am bipolar,’ viewed their need for help as self-defining, while others externalized the diagnosis, saying, ‘I have an illness,’ or ‘I have depression,’ or ‘it applied to me’.

How Medication Works
Adolescent responses to queries about how medications work resulted in the creation of 87 in-vivo codes (linked to 441 quotations). These codes, representing how medications work, were contrasted and sorted, resulting in the identification of six themes: (i) body – how medication affected the body; (ii) emotion – how medication affected feelings and mood; (iii) cognition/thought – how medication affected thinking; (iv) behavior/action – how medication improved schoolwork or decreased aggression; (v) intersubjective – how medication improved relationships with mother, peers, and teachers; and, (vi) expectation/hope – what they wished medications would do for them. Column 2 of Table 2 offers examples of adolescent responses.

In general, adolescents reported that medication helped with sleep, ‘to act right,’ and ‘do stuff better,’ representing a belief that medication produced behavioral change. They described how parents and others influenced their experience and understanding of illness and medication; with this grouping of codes, we identified an intersubjective theme. For example, respondents (7 of 20) said that they learned from psychiatrists, mothers, television, internet, books, movies, and advertisements about how medications worked and what they affected. Among the intersubjective themes one was especially common (13 of 20): medications improved relationships at home, school, or with peers. Emotionally, medications were described as: ‘it stabilizes,’ ‘it levels me,’ ‘it evens my moods,’ ‘it calms me down,’ and ‘it makes me proud of myself.’ Adolescents hoped medications would do many things: provide a cure; control their anger. They hoped medications would not stop working, or that they would relieve family stress. They hoped for an easier regimen (e.g., a once a day drink, or patch instead of pills).

Side Effects
Adolescent experience with medication side effects was linked to 27 in-vivo codes. Comparison of the shared characteristics of the quotations linked to side effect codes produced two themes: (i) body – how treatment resulted in unwanted physical concerns and; (ii) emotion – how treatment resulted in unwanted feelings. Answers commonly associated with
physical/bodily themes were: sleepiness, stomachache/heartburn, headache, hand tremors, dizziness, reduced appetite, interference with taste, weight gain, and blurred vision. Other quotations were linked to codes that were grouped under an emotional theme: worries about being too happy or hyper, worries about becoming dependent on the medication, worries about feeling high, and worry that the medications made them 'act differently.' Only 3 of the 20 reported minimal or no side effects.

Perceptions of Adherence
Forty-eight in-vivo codes (linked to 180 quotations) referenced adherence experience; these were compared and grouped under seven themes: (i) expectation/hope – how medication had either disappointed or produced the desired effect; (ii) intersubjective – how relationships had improved; (iii) emotion – how feelings had improved or not; (iv) body – negative or positive physical concerns; (v) management – the tedious nature of daily management; (vi) cognition/thought – negative or positive; and, (vii) behavior/action – better grades and fewer behavioral problems (see Column 3 of Table 2 for examples). Although more adherence experiences were coded as negative (30 of 48 negative), positive feelings were frequently (18 of 48 positive) reported. Negative experience with medication was described as: bodily side effects, difficulties remembering to take medication and worries about dependency. Positive feeling, on the other hand, was linked to improvements in the quality of family, peer, and school relationships, emotional stability, and feeling that medication worked as hoped.

In summary, themes that emerged suggest that adolescents refer to their bodies, emotions, behavior, thoughts, self, and expectation/hope when making sense of medication treatment. It also appears that perceptions of medication are drawn heavily from parents and doctors; however, peers, siblings, counselors, Internet, television, and movies were also identified and could be significant interpersonal influences upon overall experience.

Case Illustration
Alicia, a 14-year-old Caucasian female in a regular eighth grade classroom (on an Individual Education Plan), was prescribed an antidepressant at age twelve and at the time of the interview was taking an antipsychotic and a mood stabilizer. The K-SADS diagnostic interview suggested a group of Bipolar 1 symptoms, euthymic, with rapid cycling. The diagnostic interview also suggested secondary diagnoses of ADHD-combined type, separation anxiety, oppositional defiant disorder, and conduct disorder. Alicia and her mother reported adherence to the medication regimen 'all of the time.' And her Clinical Global Assessment score was near the
mid-range, suggesting that at school, with peers and family, she had normal functioning with only occasional problems.

In response to TeenSEMI questions about the need for treatment (e.g., can you tell me in your own words, why you see the psychiatrist?), Alicia reported:

I think the reason why I’m going is because I have bipolar. I felt like I was doing fine, but I guess there were kind of different things going on. (coded Diagnosis/Disorder/Symptom)

I think it’s mostly because I had a really, really bad attitude and if I didn’t like what they [parents] said, I didn’t want to hear it, and if I didn’t like it and they kept telling me, I’d start screaming, so they knew something was wrong with me. (coded Emotion)

Because when I have a bad episode, I tend to black out, I don’t remember things . . . like these glasses. I took them when I was mad and I twisted them all up and . . . I don’t remember doing it at all. My mom just told me. (double coded, Body and Behavior)

Like I would have outbursts every single day. (coded Emotion)

[what do you think caused you to have these concerns?] I’m not sure if this is really it, but the move [referring to moving out of grandma’s house after her death], because that just made my emotions go absolutely crazy. I mean I’ve lived in that house my whole life up to the 4th grade . . . That was my grandma’s house before she died, I mean, and I met my best friend at that house, and it just kind of felt like, oh my god. Look I’m just totally leaving, and it just made me really upset and made my emotions go crazy. (coded Emotion)

Well that’s when [six months after seeing a psychiatrist the first time] I first started to hear, they started saying bipolar, but also, I just remember two months into that, they had me ODD [oppositional defiant disorder], separation anxiety, and mania. (coded Diagnosis/Disorder/Symptom)

He [psychiatrist] kind of told my mom, before he told me, and then my mom sat down and explained it to me and we went and got some books from the library and we pretty much just read up on them and seen what they really were. (coded Intersubjective)

My best friend’s twin brother . . . we became really good friends . . . we [her friend] would always make jokes about him and laugh at him because he was bipolar . . . and he kind of explained to me what it was and how you have to just deal with it. (coded Intersubjective)

At first I was like, ‘no. I can’t be bipolar.’ That’s just not me. I don’t want to be it and then when I started actually seeing what was really going on, I’m just like, oh my god, I can’t believe I just said that I wasn’t this, and now I am. (doubled coded Diagnosis/Disorder/Symptom and Self)
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[so will the diagnosis of bipolar go away, do you think, over time?] No . . . its there to stay. (double coded Diagnosis/Disorder/Symptom and Self)

I only thought it was people like really crazy, and you know like the hobo thing you see on the street singing to themselves and just walking back and forth, that's what I thought they were. Really all of it. Like I was able to relate to every single part of it. (coded Self)

I also still have separation anxiety. [and where did you get that name?] The CLINIC. I got that from The CLINIC, who told my mom, then my mom told me . . . She explained it to me . . . I didn't realize like what separation anxiety is, and then she's just all like, 'well do you remember when grandma died?' And I go, 'yeah.' 'Do you remember how you won't let that go and you probably will never let that go?' I'm like 'Yeah . . . that is what separation anxiety is.' [and that again felt true to you?] yeah. (double coded, Self and Diagnosis/Disorder/Symptom)

In response to questions about how medications work, Alicia offered the following:

I started taking medicine and I would see a total different person when I took the medicine. I mean I wasn't so angry and I was able to have a good time and laugh and just have fun. (triple coded Emotion, Self, and Intersubjective)

[what went through your mind when medication was first suggested?] I felt like they thought I was crazy. (coded Self)

[do you recall what that first medication was called?] Oh I can't remember it. I know it's always on TV with the little happy dot thing. [how did that feel to you when you saw something on TV that you were taking?] I just made fun of it a lot, like me and my mom. Like if I didn't feel like taking it, my mom was like, 'go take your happy dot pill.' (coded Intersubjective)

[if a medication could do anything you wanted for the concerns you have mentioned, what would you wish it could do for you?] Nothing for me, mostly for my family. I feel that way so they won't have to go through all the pain that they had to go through (coded Intersubjective)

[what do you think the (antipsychotic) actually does for you?] It's my sleeping pill . . . I take it and I kind of get all goofy for like an hour, and then I'll be really, really hungry and I'll eat all these calories, then I'll go to bed. [so you couldn't sleep before the antipsychotic?] I could, just not as well. Like if I heard my dog walking pass my bedroom, I'd wake up and didn't know what to do, and I'd lie there for like two hours trying to go back to sleep, because I can't fall asleep without my TV on. So I'd turn on my TV and just lie there, watch TV and not be able to go back to sleep. [so the antipsychotic helps you sleep all through the night?] yeah. (coded Behavior)
[what do you think the (mood stabilizer) actually does for you?] It balances off all my . . . mood swings to where I won’t have as many. It’s like with my brother, he’ll get me mad, and before [medication] I would just straight up and hit him . . . I don’t get as aggravated . . . I mean when I was off the medicine, I would kind of like always get into trouble for aggression. I got in a fight at school. I got suspended. I got put in the court system. I beat another girl up outside of school. (coded Behavior and Emotion)

[what are some things that medication can’t do for you?] Right now I’m loving life. I have great friends. I mean there’s nothing better that I can ask for right now. It can’t just totally keep me happy all the time. It’s just the part that everybody has . . . it is normal to get a little annoyed . . . I mean it [medication] controls it [aggression] but it does not take all of it away.’ (coded Emotion and Intersubjective)

[what do you think your mother or father want medication to do for you?] Right now my mom likes the medication on me. I mean she said she couldn’t ask for anything better . . . My dad, honestly, doesn’t want me on medication, because when he was younger, he was on medication. It didn’t work for him. But my mom said that it works, and he said that he’s starting to know a difference, but he’s still kind of like, ‘well I still don’t want her on medication.’ (coded Intersubjective)

[how long do you think others believe you should take your current medication?] I don’t want to take them at all, but it’s something I have to do . . . the rest of my life . . . They told me I’m going to be bipolar for the rest of my life and I’m going to be stuck on medication. [who is they?] My mom, dad, my doctor, my psychiatrist, my counselor, my teachers, my [school] principal. (coded Intersubjective)

[some people believe that we should not take medication and fix ourselves, what do you think about that?] I thought the same way. I mean it’s kind of like I was getting brainwashed by one of my friends, and she was like, ‘by 2010 almost everybody in the world’s going to be on medicine,’ and then I started to see the real truth, and it’s just I feel like why would they put me on it if it really didn’t work? I mean are they trying to fool me or get my insurance money or something? But then I really found out. (coded Intersubjective)

How are we to understand the clinical/diagnostic and psychosocial referents in Alicia’s narrative? First, while she was ‘given’ diagnoses for bipolar and separation anxiety, clinicians turned to her mother to offer explanatory accounts: ‘He [psychiatrist] kind of told my mom, before he told me, and then my mom sat down and explained it to me.’ And while Alicia internalized an illness/disorder identity – I am bipolar (‘now I am’) – she also produced a distance between herself and the diagnosis by stating that the diagnosis (‘it’) had been given to her (‘they started saying; ‘they had me’). Moreover, while bipolar was something she had ‘for life,'
assigned to her by clinics and psychiatrists, she also saw a possible connection to the death of her grandmother and the move from her grandmother’s house. She said, ‘it just made my emotions go absolutely crazy.’ And while she thought medication worked on her aggression, it seemed also to leave some part of it unaddressed.

Alicia wondered whether her friend was correct to think that by 2010 everybody in the world would be on medication? She seemed to be saying: ‘if everybody is on medication, and I am on medication, then I am like everyone.’ This was, however, more than a simple normalization of experience. It is in this complex, intersubjective dynamic that Alicia joined others to co-produce the meaning of the medication experience. Indeed, this intersubjective dynamic is to be found in all 20 interviews. The clinical implications, we believe, are far-reaching. Psychiatrists, for example, must attend not only to prescribing the antidepressant, they must grasp how Alicia, and her mother make sense of the ‘happy dot pill.’ The television advertisement referred to in the narrative above suggests that medication targets neurotransmitters and depressive/behavioral symptoms; but mother and daughter are equally influenced by the drug’s implied power to create happiness. Alicia and mother found humor in the commercial by joking about the tedious nature of daily medication management. Of the intersubjective influences on medication experience perhaps most significant was Alicia’s belief that taking medication both pleased her mother and resulted in fewer fights with her brother. Alicia’s motivation to adhere to the medication was related in part to her perception that it helped make peace in the family. This finding suggests that medicating adolescents is symbolically medicating a family because the effects of medication generate meanings that implicate an entire family system (Chubinsky & Rappaport, 2006; Oldani, 2009; Rappaport & Chubinsky, 2000).

**Discussion**

Alicia’s medication experience presents several possibilities for further inquiry. Peter Conrad (2007), for example, has recently looked at how social and psychological problems are increasingly framed by and acted upon through biomedical assumptions. Drawing on such work, one might explore the relationship between medicalization and psychiatric medications by examining how Alicia simultaneously adopts and accepts both the bipolar diagnosis and psychosocial explanations of her difficulties. For example, we might ask how psychiatric medicalization produces fundamentally new possibilities for conceptions of self, as determined by the medication experience. Moreover, asking such questions can highlight the analytical limitations of concepts such as medicalization and the globalization of pharmaceuticals. Thus while one can easily join Alicia in
imagining a world in which everyone is on psychiatric medications, globalization, like medicalization, is a not a sufficiently rich concept to provide an adequate account of how individuals ultimately make sense of their medication experiences. These concepts, for example, would not help us conceptualize how for Alicia the ubiquity of medication becomes a potential defensive projection aimed at normalizing stigma or shame about her illness or medication experience. David Karp shows in his work with teenagers how anti-depressants in schools produced an intersubjective experience of stigma (Karp, 2006). Whichever direction the cause and effect might run in these instances, there is little doubt that for Alicia the hoped-for symptom-focused biomedical model is just one of many ways in which she makes meaning of psychiatric medications.

Over the set of 20 adolescent respondents, personal and interpersonal themes of adolescent psychotropic treatment might be understood as different points of view through which adolescents understand and take action related to: their illness concerns; their need for medication treatment; their perceptions of how medications work; their responses to parental and other influences upon medication treatment; and their everyday management activities. The theme of expectation and hope seems particularly central to their experience. It is in the space between the successful and disappointing medication treatment that adolescents wonder: ‘why take medications,’ ‘what will they do for me,’ ‘will they harm me,’ and ‘how will I manage them.’ Our findings suggest that adolescents will deploy one or several personal and interpersonal life domain dimensions to answer these questions and in doing so make psychotropic treatment meaningful.

As is the case with all of those interviewed for this study, Alicia’s particular diagnosis and medication experience is mediated by complex social dynamics. Observation and interpretation of adolescent medication effects are shaped by family, community, cultural, and personal belief and attitude toward: the diagnosed illness; how diagnoses are made; and the treatment, including the nature of the relationship between practitioner and treatment recipient. Our model for representing adolescent medication experience and management is summarized in Figure 1. The model is comprised of five elements of a medication experience, represented vertically (highlighted in gray) as the socio-cultural dimension: (i) problem, (ii) prescription assessment, (iii) access and payment, (iv) monitoring and interpreting effects, and (v) reporting effects. Furthermore, pharmaceutical interests, insurance/payment policies, and the organization of local mental health services set the parameters for the medication experience. For example, the local service provider may be resource depleted or influenced by a single or reductionist model of the relationship between mind and body. Horizontally we have depicted the
<table>
<thead>
<tr>
<th>Personal Interpersonal Dimension</th>
<th>Socio-cultural Dimension</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Socio-cultural Dimension</td>
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<tr>
<td></td>
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</tr>
<tr>
<td>Emotion</td>
<td>Cognition</td>
<td>Body</td>
<td>Intersubjective</td>
<td>Social Relations of Medication Management</td>
<td></td>
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</tr>
<tr>
<td>Problem and diagnosis</td>
<td>What emotions get indexed to a diagnosis?</td>
<td>What beliefs and attitudes get indexed to a diagnosis?</td>
<td>How is the body indexed to a diagnosis?</td>
<td>Parent, Peer, Teacher, Clinician expectations</td>
<td>Beliefs and attitudes about the illness and diagnosis?</td>
<td></td>
</tr>
<tr>
<td>Medication prescription and clinically hoped-for effects</td>
<td>What emotions get indexed to desired effects?</td>
<td>What beliefs and attitudes get indexed to desired effects?</td>
<td>How is the body indexed to a desired effect?</td>
<td>Beliefs and attitudes about medication producing the desired effect?</td>
<td>Periodically, who decides the category and dosage for or with the adolescent?</td>
<td></td>
</tr>
<tr>
<td>Access and payment</td>
<td>What emotions get indexed to payment and service access?</td>
<td>What beliefs and attitudes get indexed to paying and service access?</td>
<td>How the body is indexed to paying and service access?</td>
<td>Beliefs and attitudes about payment and service access?</td>
<td>On a regular basis, how are the medications paid for and who assures access to medication?</td>
<td></td>
</tr>
<tr>
<td>Monitoring adherence and interpreting gap between hoped-for and actual effects, including unintended side effects</td>
<td>What emotions can be indexed to compliance, expected, and actual effects?</td>
<td>What beliefs and attitudes get indexed to compliance, expected, and actual effects?</td>
<td>How is the body indexed to compliance, expected, and actual effects?</td>
<td>What are the feelings, thoughts, and beliefs about compliance, monitoring, and the actual effects of medication?</td>
<td>On a daily basis: Who monitors compliance? Who monitors desired effect? Who monitors actual effect? Who monitors unintended side effect?</td>
<td></td>
</tr>
<tr>
<td>Reporting effects, including unintended side effects</td>
<td>How are medication effects on emotions reported?</td>
<td>What beliefs and attitudes about effects are reported?</td>
<td>How are medication effects on the body reported?</td>
<td>Among all involved, who reports medication effects to whom?</td>
<td>On a daily basis: Who reports what to whom?</td>
<td></td>
</tr>
</tbody>
</table>

**Figure 1** Socio-cultural, personal, and interpersonal matrix of adolescent medication experience and management.
subjective (i.e., personal) and intersubjective (i.e., interpersonal) dimensions of the adolescent psychopharmaceutical experience.

The subjective aspect of medication treatment has two dimensions and addresses the degree and nature of involvement, passive or active (Longoher, Floersch, & Jenkins, 2003b), in making sense of the biopsychosocial domains; Alicia, for example, was actively engaged in making a psychosocial claim about her illness: she wondered about the effect of her grandmother’s death on her intense affect. And while one might see this as active resistance to the biological diagnosis, Alicia just as actively embraced her bipolar diagnosis: she engaged with her mother to determine the cause of her affective storms. Moreover, she reported that medication reduced aggression and also linked the medication’s effect to an acceptance of the correct diagnosis, ‘... it balances off all my... mood swings to where I won’t have as many.’ Alicia’s references to the biopsychosocial domains of emotion, cognition, and body show us the personal and interpersonal dynamic of her medication experience and the sociocultural milieu organizing her experiences around DSM-IV categories and medication treatment. The aggregate data and case illustration remind us of the danger of reducing our assessment of medication treatment to its biological or clinical effects; assessment must include attention to extra-clinical, sociocultural effects.

The intersubjective dimension also refers to how passively or actively the adolescent engages others, (i.e., parents, peers, teachers, clinicians, and friends) the Internet, popular magazines or culture, and libraries in gathering information that shape how they make sense of the psychototropic experience. Alicia, for example, was influenced by the Zoloft commercial, as well as by a peer’s brother who had been diagnosed with bipolar disorder. She also took medication, in part, to please her mother. At the same time, her father remained skeptical of the pharmacological treatment. Indeed many adolescents in this study reported that fathers were not engaged in treatment decisions, and were similarly ambivalent. The influence of skeptical fathers on their children presents a challenge: when parents disagree over medication use, how does this affect the medication experience?

The system of medical, clinical diagnosis produces a particular intersubjective field for making meaning of everyday medication experience. And while it might be easy for some to imagine that psychiatric diagnoses are made based solely on ‘detecting signs that point to objective, measurable parameters’ (Verhaeghe, 2004, pp. 17–18) in practice psychodiagnostics always requires interpretation. Although at the time of Alicia’s interview bipolar disorder was the principal diagnosis, she had been given several diagnoses over the years. Clinicians prescribing medications are obligated to connect the suggested use and type of drug
(e.g., anti-psychotic, mood stabilizer, psychostimulant, etc.) to particular diagnoses. Yet, these data suggest that it does not necessarily follow that the recipient accepts the diagnosis and the connection between a specific disease/disorder and its associated medication. Diagnosing youth, moreover, presents serious challenges. Alicia’s history of multiple diagnoses illustrates this challenge and raises the question: which diagnosis did she identify with and why?

Table 3 compares the self-reported diagnosis of the 20 participants with that of the K-SADS-PL. The comparison shows that 13 of 20 adolescents did not report a disjuncture between their diagnostic understanding and the K-SADS-PL, a standard symptom-based assessment. For 7 (highlighted in gray), however, there was a disjuncture, raising questions about how they experienced the gap between the clinician’s diagnostic interpretations and their own understandings of the problem and associated medication treatment.

**Conclusion**

For most people who take aspirin for headaches, the hoped-for effect is credited to the power of the drug. Between the expected (hoped-for or desired) and the experienced effects of medication, there exists a phenomenological, subjective and intersubjective gap (Longofer & Floersch, 2004; Longhofer, Floersch, & Jenkins, 2003a). When medicine is believed to be the agent that delivers the expected effect, the gap between desired and experienced effects is narrowed. In such cases, patients are likely to interpret treatment effects as tangible and focused. On the other hand, this gap between expectations and experience may be quite large when the anticipated effects of a medication are less well defined and when others assert their expectations (Floersch, 2002). Thus, in relation to reducing or eliminating psychiatric symptoms like depression, anxiety, and irritability, the expected effects may be elusive, transient, or difficult to pinpoint. In the present study, Alicia, for example, regarded the medication’s role in reducing aggression in positive terms; yet she also recognized, ‘it doesn’t take it all away.’ She seemed to be asking: how much aggression is normal? Or: how much is left over after the medication takes care of its portion? There was another gap between her expectation that the medication will help her and that it would help others: ‘Nothing for me, mostly for my family.’ This gap represents a subjective and intersubjective space within which the medication recipient (or others in their network) observes, monitors, and interprets. Meanwhile, adolescents’ interpretations of medication effects are always embedded in the broader context of sociocultural factors related to mental health services and biopsychiatry.
### Table 3
Participant self-report diagnosis compared with research, KSADS-PL diagnosis

<table>
<thead>
<tr>
<th></th>
<th>Self-Report Diagnosis</th>
<th>Primary KSADS-PL Diagnosis</th>
<th>Second KSADS-PL Diagnosis</th>
<th>Third KSADS-PL Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Bipolar</td>
<td>Bipolar</td>
<td>ADHD</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Seizures, does not know</td>
<td>Schizophrenia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Bipolar</td>
<td>Bipolar</td>
<td>Separation Anxiety</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>ADD</td>
<td>ADHD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Bipolar, ODD, Anxiety</td>
<td>Bipolar</td>
<td>Conduct Disorder</td>
<td>ODD</td>
</tr>
<tr>
<td>6</td>
<td>Depression</td>
<td>Major Depressive Disorder</td>
<td>PTSD</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Bipolar, ADD, Depression</td>
<td>Bipolar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>ADHD, ODD</td>
<td>Bipolar</td>
<td>ADHD</td>
<td>ODD</td>
</tr>
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<td>9</td>
<td>Depression, Bipolar</td>
<td>Major Depressive Disorder</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Bipolar</td>
<td>Bipolar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>ADHD, Depression</td>
<td>Major Depressive Disorder</td>
<td>ADHD</td>
<td>Panic Disorder</td>
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<tr>
<td>12</td>
<td>Mood Disorder</td>
<td>Bipolar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Depression, Eating Disorder</td>
<td>Major Depressive Disorder</td>
<td>Eating Disorder</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Bipolar, ADHD, Depression, Anxiety</td>
<td>Substance Induced Mood Disorder</td>
<td>ADHD</td>
<td>ODD</td>
</tr>
<tr>
<td>15</td>
<td>ADHD</td>
<td>Bipolar</td>
<td>ADHD</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Forgot – does not know</td>
<td>Eating Disorder</td>
<td>Avoidant D/O</td>
<td>Enuresis</td>
</tr>
<tr>
<td>17</td>
<td>ADD</td>
<td>Major Depressive Disorder</td>
<td>ADHD</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Did not give a name</td>
<td>ADHD</td>
<td></td>
<td>Enuresis</td>
</tr>
<tr>
<td>19</td>
<td>Depression, ADD</td>
<td>Bipolar</td>
<td>ADHD</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>ADD</td>
<td>ADHD</td>
<td>Enuresis</td>
<td></td>
</tr>
</tbody>
</table>
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NOTES

1. This outpatient research protocol was reviewed and approved by the University of Hospitals Case Medical Center Institutional Review Board for Human Investigation. The parents/guardians of the research participants provided written informed consent and all adolescents provided written informed assent prior to study participation. The interviews conducted under the auspices of this study took approximately six hours. Parents received $50 and adolescents $65, respectively as honoraria.

2. Prior to administering the diagnostic assessment, the rater met adequate inter-rater reliability standards (kappa > .85) on five consecutive interviews while observing a trainer-rater and on five consecutive interviews while leading the interview; a rater’s kappa of ≥ .85 indicates that eighty-five out of hundred conclusions would reliably match other raters trained with the same protocol.

3. The type of coding procedure used in this analysis is a synthesis of the following grounded theory approaches: Boeije, 2002; Charmaz, 1990, 2006; Glaser & Strauss, 1967; Muhr, 1993; Sivesind, 1999.

4. Indirect support for these findings includes research that has emphasized that adult experience is mediated by culture, mental health systems, and medicalization processes (Conrad, 2007; Floersch, 2002; Jenkins et al., 2005; Karp, 2006; Kirmayer, Young, & Robbins, 1994; Kleinman 1988).

5. Results from one clinical drug trial have noted that a medication’s intended effect was moderated by the degree of family conflict (see Townsend, Demeter, Youngstrom, Drotar, & Findling, 2007).

REFERENCES


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