Perspectives on Psychotropic Medication Treatment Among Young Adults Formerly Served in Public Systems of Care: A Thematic and Narrative Analysis

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ABSTRACT This study examines the perspectives of psychotropic medications held by young adults with mood disorder diagnoses. This article presents an analysis of qualitative interviews with 52 young adults who had been involved with public systems of care during adolescence and had used psychiatric medications. A concatenated analytic approach was used. First, we used a thematic analysis across cases, then a narrative analysis within selected cases. Two main themes emerged from the thematic analysis that captured aspects of the experience of taking medication. First, young adults described the effects of the medications and how they thought the medications were working. They described the impact on their moods, thinking, bodies, and functioning, and the ways in which these effects related to their lives. Second, the process of taking medications emerged as an important aspect of the medication treatment experience, including the trial-and-error nature of treatment and interactions with psychiatrists. The narrative analysis within cases identified that some youth created a medication narrative composed of three elements: why medications were needed, what medications do, and participants' outlook on future medication use. These narratives are helpful in understanding prior patterns of service use and are instructive in framing young people's future intentions to use medications. Findings support the importance of eliciting the perspectives of young adults about their treatment and ensuring that services are designed and delivered in developmentally appropriate ways tailored to this group.

KEYWORDS: psychotropic drugs, young adult, mental health, medication adherence, personal narratives

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Adolescents served in public systems of care such as the juvenile justice and child welfare systems have elevated rates of mood disorders as compared with their peers in the general population (Garland et al., 2001;

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Keller, Salazar, & Courtney, 2010; McMillen et al., 2005; Merikangas et al., 2010; Teplin, Abram, McClelland, Dulcan, & Mericle, 2002) and are thus at elevated risk for mental health problems in young adulthood (Copeland et al., 2013). In a longitudinal study of youth with a mental disorder who were involved in juvenile detention, approximately 1 in 5 youth continued to experience symptoms from adolescence into adulthood (Teplin, Welty, Abram, Dulcan, & Washburn, 2012). Psychotropic medications are often a central part of treatment for mood disorders in adolescents (i.e., Bowden et al., 2012; Crismon & Argo, 2009; Gaynes et al., 2009; Rush, 2011), yet many youth involved in public systems stop using medications in young adulthood after they leave these systems (McMillen & Raghavan, 2009). Although some evidence has suggested these young adults choose to discontinue medication treatment (McMillen & Raghavan, 2009), little of the available evidence is helpful toward understanding *how* these young adults experience medication treatment and *why* they decide to continue or discontinue treatment. Prior studies have emphasized the importance of understanding the process and experience of taking medications beyond the physical effects, and researchers have recommended further exploration in specific populations (i.e., Davis-Berman & Pestello, 2008; Moses, 2008). To better understand the subjective experiences of young adults taking medications and their decision-making process when choosing to continue or discontinue medications in young adulthood, we explored the perspectives toward psychotropic medications of young adults with mental health diagnoses who have transitioned out of public systems of care.

Why Focus on Young Adults Involved With Public Systems of Care?

Our focus on the medication experiences of young people who have transitioned out of public systems of care was driven by several factors. First, youth in the child welfare system have high rates of both psychotropic medication treatment (i.e., Raghavan et al., 2005; Rubin et al., 2012) and polypharmacy (i.e., dosReis et al., 2011; Zito et al., 2008), raising questions about the appropriateness of treatment these youth have received (McMillen & Fedoravicius, 2007). Over their time in the system, some young people have received multiple diagnoses and multiple medications (Narendorf, Bertram, & McMillen, 2011), and have had treatment experiences that lead them to question whether they actually need medications when they have the opportunity to decide for themselves. Second, given the structure of the child welfare and juvenile justice systems, both of which involve the courts in mandating treatments, youth in the care of these systems might have experienced treatment as a decision forced upon them rather than a choice in which they had an active role. Prior work with adolescents has shown that those who felt coerced to take medications were less likely to report the intention to continue medication treatment when they could decide for

themselves (Moses, 2011). A third reason for focusing specifically on the views of young people who have exited public systems is related to the limited support systems that these youth have as they leave the child serving systems that have supported them and transition to independent living as young adults (Osgood, Foster, & Courtney, 2010). Many of these youth rely on support from social workers and other mental health professionals, making it critical that these professionals understand how to engage these young people in conversations about mental health treatment in ways that respect their views and support their decisions about the role of medications in managing their symptoms.

The Meaning of Psychiatric Medications

Prior work on how people make meaning of their medication treatment has not only provided a foundation for understanding how people make sense of this treatment but also offered a lens for examining which elements might be distinct for young adults at this developmental stage who are leaving public systems. Anthropological, sociological, and historical studies of illness and medication treatment have repeatedly demonstrated the importance of illness representation, or the symbolic constructions (i.e., meaning making) of routine uses of medication in the illness experience (Applbaum, 2009; Biehl & Moran-Thomas, 2009 Ecks, 2005; Greene, 2004; Healy, 1997; Oldani, 2009; Lakoff, 2005; Rose, 2003; Rubin, 2007; Whitmarsh, 2009). Studies that have examined the meaning of medication for people taking antipsychotic medications have found that subjective experiences with medications influence individuals' decisions to follow treatment recommendations, and can be an important contributor to clinical outcomes (Awad, Hogan, Voruganti, & Heslegrave, 1995; Awad, Voruganti, Heslegrave, & Hogan, 1996; Garavan et al., 1998). Bentley's (2010) study of medication treatment among adults with serious mental illness in a residential program found a variety of representations of the role of medication, including medications as a positive force, a tolerated fact of life, a source of gratitude and triumph over symptoms, a prominent part of the story of mental illness, a protection of humanness, and an internal and individual experience. Bentley's work emphasized the integral nature of medication experiences with the overall experience of managing a serious mental illness, and highlighted the need for social workers to facilitate conversations specifically about the perceived effects and role of medications in treatment.

Importance of a Developmental Perspective

Prior work on the subjective meaning of medications has largely focused on adults with serious mental illness who have developed their understandings of medications over a long history of treatment. Studies with adolescents provide a contrasting perspective of those who are newly experiencing medication treat-

ment. One qualitative study of adolescents suggested that adolescents believed medications helped them with improving behavior, sleep, relationships, and calming down; further, those beliefs were informed by different sources in their environment including their doctors, families, peers, and the media (Floersch et al., 2009). For young adults who are trying to manage mood disorders and who have recently taken ownership for their own treatment, the perspectives on the role of medications in their treatment is likely distinct from that of either adolescents or adults. Theoretical work focused on understanding young adult service use has stressed the importance of considering multiple contextual factors, including the structure of the service system, influential social relationships, and the developmental stage of youth who are transitioning into adult social roles and taking responsibility for their own health and treatment (Munson et al., 2012). The unique situations of youth exiting public systems of care during this stage of development warrant added attention to understand the perspectives of these youth regarding medication treatment.

Medication Use Narratives

One way of incorporating the historical and developmental aspects of young adult medication perspectives is through the analysis of narratives. Narratives are stories that give meaning to an experience or event by linking motive, actions, and consequences, and by doing so, narratives can function as guides for future actions (Garro & Mattingly, 2000). Narratives of specific service use, such as use of psychotropic medications, can help researchers, scholars, and practitioners to better understand how and why people make decisions to use or discontinue services (Bissell, Ryan & Morecroft, 2006). Existing research that has examined medication narratives in adolescents found the narratives had three components that answered fundamental questions: Why do I need medication?; What do the medications do for me?; and How do medications figure into my life in the future? (Floersch, Longhofer, Kranke, & Townsend, 2010). Young adults exiting public systems are engaged in a similar process of making meaning of their experiences, yet these experiences are likely to differ substantially from those of adolescents who are living in their family home.

This study used a combined thematic and narrative approach to address several gaps in the field's understanding of young adult perspectives on psychiatric medication treatment. This article focuses on a group at heightened risk for negative outcomes: young adults currently struggling with mood and emotional challenges, all of whom have histories of mood disorder diagnoses and involvement in public systems of care during childhood and/or adolescence. We examined qualitative data from both the young adults who chose to continue medication treatment and those who discontinued taking medications in young adulthood. We first looked across cases to answer our primary research question: What are

the experiences with psychotropic medication treatment among young adults who have exited public systems of care? Then, we looked within cases to examine the following questions: Do young adults who have left public systems and are transitioning to adulthood create medication narratives that assist them in making sense of their experiences of medication treatment? If so, do these medication narratives help to better understand their decisions and intentions for medication use as they transition to adulthood?

Method

Sampling and Participants

Participants were recruited as part of a larger study of mental health service use in the transition to adulthood that was conducted from 2008 to 2010. Potential participants were recruited through flyers placed at agencies, institutions such as community colleges, and community locations. Specifically, we were interested in young people who had used services before their transition to adulthood and reported ongoing need for services as young adults. Potential participants were provided with information about the study and screened for inclusion by phone. Participants met criteria if they had received a diagnosis of a mood disorder during childhood, used Medicaid-funded mental health services during childhood, used one additional public system of care (e.g., child welfare, juvenile justice, public welfare, special education), and reported currently struggling with mood and emotional difficulties. Study eligibility on history of service use and diagnosis was determined using a standardized tool based on screening questions used in the Diagnostic Interview Schedule (Robins, Cottler, Bucholz, & Comptom, 1995). In addition to these criteria, participants had to respond affirmatively to the question, "Are you still struggling with mood and emotional difficulties?" We excluded those currently experiencing psychosis, using illegal/unprescribed substances, or developmental disability services. Approximately 25% of young adults who were screened met criteria for study inclusion. All study procedures were approved by the Human Subjects Review Board and have been described in prior work (Munson, Scott, Smalling, Kim, & Floersch, 2011).

To focus the current analysis on the use of psychotropic medications, we used a subset of participants from the larger study. All participants in the current study (N = 52) were between ages of 18 and 25 years and reported taking psychotropic medications at some point in their lives. The majority of the sample was female (71%) and youth of color (68%). Almost all participants reported high levels of depressive symptoms (96%) but less than half of the sample was currently taking medications (46%). The most commonly used medications were antidepressants, although significant percentages were also taking mood stabilizers, anti-psychotics, and stimulants. Table 1 presents descriptive statistics of the study sample.

Table 1
Sample Characteristics (N = 52)

	% (*n*)	Mean (*SD*)
Age		20.90 (2.05)
Female	71 (37)	
Black/multi-racial	68 (35)	
Mood disorder diagnosis in childhood	100 (52)	
Current depression (CES-D)	96 (50)	
Current psychiatric medication use	46 (24)	
Antidepressant	77 (18/24)	
Mood stabilizer	46 (11/24)	
Antipsychotic	42 (10/24)	
Stimulant	29 (7/24)	

Interview Procedures and Measurement

A semi-structured interview protocol with seven core questions was used to gather information about mental health service use: (a) "Has your mental health service use changed since you turned 18?" (b) "How did you transition to services after turning 18?" (c) "Was there any particular mental health/social service that you found particularly helpful or not helpful?" (d) Have you run into difficulties getting mental health services?" (e) "Do you feel you need mental health services at this time?" (f) "Do you have the money/resources to pay for them?" (g) "Of all the reasons not to seek services, why are you not seeking services?" Probes were used to elicit narratives of service use and to gain additional information. Notably, interviewers did not ask questions specifically about medication use but asked about mental health service use broadly.

Participants also responded to several structured instruments. Questions about past and current medication use and compliance with medications were based on the Service Assessment for Children and Adolescents (Stiffman, Horwitz, & Hoagwood, 2000). Participants' level of depressive symptoms was determined using the Center for Epidemiological Studies Depression Scale as part of the interview (Locke & Putnam, 1971).

Analytic Strategy

We used a two-stage concatenated approach to analysis. For the first step, we used a thematic analysis based on grounded theory techniques to explore the perspectives of our sample toward psychiatric medications. To develop an initial codebook, we used a constant comparison approach with two analysts doing line-by-line in vivo coding across five interviews. This codebook was used to code another 15 interviews and was then refined through discussion to

create a final version used to code the rest of the interview data. Once all interviews were coded, analysts engaged in a second round of constant comparison, examining content and meaning of the axial codes to derive themes and dimensions of medication experience. The second step involved a narrative case analysis of the overall story of medication use within cases to answer our questions about whether young adults constructed medication narratives and how such narratives influenced their intentions to use services in the future. We selected the 15 most densely coded cases from the thematic analysis and began a new analysis guided by sensitizing codes from prior work (Floersch et al., 2010). An iterative process was used to develop and refine the codebook and code for narratives within cases. We examined these narratives with a narrow focus on the overall pattern of medication use and its relation to indications of intentions of future medication use. This article presents case examples that represent young adults who displayed commitment to medication treatment, appeared ambivalent about medications, and did not intend to take medications in the future.

Results

Stage 1: Thematic Analysis

The first stage in the analysis was focused on answering the following question: What are the experiences of young adults who have exited public systems with psychotropic medication treatment? To answer this question, we examined all comments related to psychotropic medications and identified themes based on the content. Two main themes captured overall experiences with medications: (a) what medications do to me; (b) what it is like to get medications. Table 2 illustrates the themes and dimensions of youth's perspectives on psychiatric medications.

Effects of medications: What medications do to me. We found that youth frequently talked about medications in relation to their perceptions of the medication's effects across four dimensions: (a) body, (b) feelings/mood, (c) thinking/cognitive functions, and (d) relationships and/or daily functioning. Many participants had patterns of intermittent medication use and spoke about the differences they observed across these dimensions when they were on or off medications. Descriptions of medications as helpful were often presented in the context of the differences youth observed when they were or were not taking medications. Young adults also spoke about their experiences across these dimensions in both positive and negative ways.

Medications work on my body. Depictions of the physical effects of medication included explanations of the way medications work in the body and reports of physical effects. Some participants used biological or medical terms to present their understanding of how medications work.

Table 2
Youth Perspectives on Psychiatric Medications: Themes and Dimensions

Theme	Dimensions	Exemplar quotation
Effects of medications (*n* = 127 coded passages)	Body	*It balances the chemicals in my brain, 'cause that's what my mood disorder is, my chemicals are off.* [Participant #16]
	Feelings/mood	*With medication it's like I have mood swings, but not as much, and I don't get angry as fast, or I don't get sad as fast. It's like with the medication it calms me*. [Participant #11]
	Thinking/ cognitive	*Once I started getting back on the medication I was able to make my mind right and be able to think a little bit further and figure out, plan ahead and figure out what I can and cannot do and what is more possible than anything else.* [Participant #15]
	Functioning/ relationships	*It's like I don't want to be around people, I don't want to talk to people, but when I'm on my meds I'm able to deal with being around people*. [Participant #26]
Process of medication treatment (*n* = 74 coded passages)	Psychiatrists don't understand	*My med doctor doesn't listen to me. They don't listen to what I want to do about my meds and what meds I want to be on. Like right now, I'm being put on something I don't even want to be on*. [Participant #24]
	Trial-and-error medication	*I just feel like she just wants to just put me on all different type of medicine. I just try to tell her some stuff. I don't try to tell her as much, because I just think she think I'm just an experiment. Well, I don't just think* [it's just] *her— I just think a lot of doctors just, "Oh, you should try this."* [Participant #7]
	Relationship to other treatments	*Because I'm a talkative person and . . . I dealt with my anger talking it out to God or talking to myself. So that helps me. It [counseling] soothes me better than me popping a pill in my mouth*. . . . [Participant #20]

> *They attack the central nervous system and they sedate it. They're sedatives, you know, and they calm you down . . . they stop like endorphins from flying around your brain.* (Participant #14)

Others described physical effects in personal terms, often in reference to adverse effects:

> *When they put me on Ritalin, I got quiet and I did my work . . . but I didn't eat and my stomach was hurting constantly all the time.* (Participant #35)

Medications change my moods. Many participants described medications as being helpful in controlling moods, especially anger and sadness: "*With medication, it's like I have mood swings, but not as much, and I don't get angry as fast or I don't get sad as fast*" (Participant #11). However, these helpful effects were not without a perceived cost in that several participants described the medication effects as flattening their emotions: "*Honestly, if I wanted to, I couldn't force a tear. I can't get emotions to come out when I take my medications*" (Participant #37). In some cases this flattening contributed to participants' decisions to reduce or stop the medications so that they could experience the full range of their emotions. For example, one participant said,

> *I just felt like being depressed and letting the situation that was happening just go. I didn't really want to hide it or suppress it with the medication, so I just didn't take it.* (Participant #26)

Medications change my thinking. Another perceived effect of medications was their impact on thinking, which included improved focus and improved ability to process and problem solve. One participant noted that with medication, "*I was able to make my mind right*" (Participant #15), indicating that the effect of medications brought him closer to his perception of how his mind should function.

The perceived physical, emotional, and cognitive effects of medications also had consequences for daily functioning. Participants noted the decision to not take medication often had negative consequences such as problems with finding and keeping a job and limited social interaction. For example;

> *I know when I don't take them [medications] that there's a big change in the way that I . . . I don't want to talk to people, but when I'm on my meds I'm able to deal with being around people.* (Participant #26)

Participants who were parents conveyed their mixed feelings about the positive effects of medications on controlling their moods around their children but also reported that adverse effects such as drowsiness had a negative impact on their ability to be present for and attentive to their children.

The different ways that medications affected participants across their bodies, moods, thinking, and functioning were sometimes presented in relation to each other. Some participants noted that when they felt they had greater control of their emotions, they were able to think more clearly, which in turn, improved their ability to work, to relate to others, and to be a parent. For example, one participant's comment was typical of many: *"If you're screwed up emotionally, mentally you're going to be screwed up too. It works hand-in-hand"* (Participant #15). In sum, participants' perceptions of medications effects and how medications work across multiple dimensions demonstrated the ways in which young people made sense of medication treatment and underscored that these perceptions were often formed through their experiences of taking and not taking medications.

Getting medication treatment. The second theme identified in the interview data was the process involved in getting medication treatment. Participants spoke of their interactions with psychiatrists, the trial-and-error process of finding the right medication and the right dosage of a medication, and they voiced concerns about the quality of the treatment they had received. These comments provided a sense of the contextual elements that shaped their perceptions of medication treatment.

Psychiatrists don't understand. Many participants commented about their interactions with psychiatrists, especially interactions in which they did not feel the psychiatrist was listening to what they were saying about their experiences. These interactions were critical to both the young person's experience of medication treatment and their assessment of treatment credibility. Most expressed the feeling that psychiatrists did not respect them or listen to their perspectives:

> *. . . The med doctor . . . she just basically told me what's good for me, what's bad for me and what I need to do . . . I've been on over 30 different medicines. . . . I know what works, and she just treats me like a child.* (Participant #24)

Psychiatrists' lack of attention to their clients' perspectives and experiences combined with frequent medication changes contributed to the young adults' negative perceptions of their psychiatrists. In contrast, a few participants described positive treatment experiences characterized by a psychiatrist who listened attentively to what the young person had to say:

> [provider name] *is the guy who gives me medication . . . I tell him how it makes me feel, he doesn't try to keep me on it and up the dose . . . he's going to go ahead and try other things.* (Participant #32).

Participants also described frustrations resulting from a lack of continuity of care. Those who saw several psychiatrists noted how receiving care from multiple providers affected treatment:

> *You talk to so many different psychiatrists, and they're different people with different views and different values and different you know everything. So you may seem, you know, different to a different psychiatrist than you would to another psychiatrist, you know, your diagnosis and everything else may be different.* (Participant #14).

Across participants, it was clear that young people valued providers who solicited their perspectives and listened to what they had to say.

It's just continuous trial and error. Medication treatment was described by several young people as a trial-and-error process. Young people attributed this process to the nature of mental disorders that are difficult to treat and the inability of the doctor to precisely understand the patient's experience. One young person described this experience by saying,

> *If you're a doctor and you're working to make people feel better, you know you've been sick before. . . . It's totally different with mental disorders, because the other person can't tell how the other person is feeling, so it's . . . just continuous trial and error.* (Participant #14)

For some, the trial-and-error process led to finding a medication that worked reliably:

> *They didn't know exactly what my diagnosis was. There was a lot of trial and error . . . when they found the right medication, they decided to stick to it. It's been my same medication for almost 4 years.* (Participant #15).

Others described the difficulty that changing medication created: *"They just be changing my medicine. . . . I don't like that. I like to be normal. Don't have me all discombobulated"* (Participant #5). When young adults found the right medication that worked, they talked about it with confidence, *"They asked me what I would take and I said 'Nothing, other than Abilify.* (Participant #57), and even fondness, "*I started taking my old Geodon and I feel so much better*" (Participant #36).

In addition, some questioned the trial-and-error practice of polypharmacy, and some young people wondered about the motivations of psychiatrists: *"I feel I was a guinea pig. They tried me with everything that came out"* (Participant #7); and *"You know, a new drug comes on the market and the drug companies pay the doctors to prescribe it to people"* (Participant #14).

Medications and other treatments: They jump the gun straight to medication. Psychiatric medications are just one type of treatment that can be used in conjunction with other types of mental health services. Several participants talked about medications specifically in relation to other types of treatments, and stated their preferences for therapy instead of or in conjunction with medications. Many participants reported feeling that medications were prescribed too quickly: *"I think that*

sometimes people kind of jump the gun straight to medication" (Participant #22). Others expressed an opposing viewpoint, stating that with maintenance medications, they had no need or desire for counseling: *"I feel like I can do it on my own if I have the medication. I don't need the counseling, any of that"* (Participant #36). Indeed, participants expressed a variety of perspectives relative to their preferences for therapy, medications, or a combination.

Stage 2: Narrative Analysis

The second stage in our analysis was guided by two questions: "Do young people who have left public systems and are transitioning to adulthood create medication narratives to assist in making sense of their experiences of medication treatment?"; and, if so, "Do these medication narratives help practitioners to better understand the decisions and intentions of these young adults regarding medication use as they transition to adulthood?"

Within cases, we found evidence that young people do create medication narratives that responded to three questions: (a) What is wrong with me that a medication addresses? (b) What do the medications do to address the problem?; and (c) What is the role of medications in my future? These elements were instructive in understanding current medication use and provided insights into the ways that participants thought of the role of medication in their future lives. We specifically examined these narratives in relation to the young person's service use history and their outlook on future medication use to determine whether the medication narratives were instructive for developing a better understanding of service use decisions generally. Through these analyses, we noted prominent themes among young adults, including (a) the growing sense of independence and maturity that shaped their attitudes toward taking medications, and (b) the role of illegal substances, which some presented as an alternative method of managing symptoms. In addition, these narratives assisted in understanding the contextual factors that shaped medication use and medication use decisions.

To illustrate these factors, we have compiled case exemplars of the differing attitudes and outlooks toward future medication use that we found across the narratives. Through our analyses, three conceptually distinct outlooks emerged that captured the narratives across these cases: committed to medication, ambivalent toward medication, and no interest in medication.

Committed to Medication

Young adults whose narratives fell into this group were currently using medications, expressed the intention to continue, and had service use histories characterized by either continuous use or a single gap in treatment. For those who had experienced an interruption in service use, the time off medication was pre-

sented as a break that helped the individual understand why he or she needed medication. These young people tended to attribute their symptoms to biological causes, and generally regarded mental health problems as a disease for which treatment with medication was an appropriate and reasonable approach. These participants generally had access to treatment, perceived their experiences with medications as helpful, and had support systems that supported their commitment to taking medications.

Case Example 1

Case 1 is a 19-year-old Caucasian male who is living in his grandmother's home and is currently taking Geodon. He first started taking psychotropic medications for emotional and behavioral problems at age 13 years, and his history includes involvement with publicly funded Medicaid mental health and child welfare systems. He was a resident in a group home until he aged out at 18 years old, and moved to his grandmother's house where he stopped taking medications. He attributes this decision to a lack of a support system of people who would prompt him to take medications and attend appointments.

He described significant anger problems that he characterized as "*not normal*" and described his diagnosis of bipolar disorder as "*a chemical imbalance*" that is long-term, requiring ongoing management. A central feature of his medication narrative was his satisfaction with finding a medication that works for his symptoms. Before leaving the group home, he had come to understand that Geodon was the right medication for him: "*I was on a couple different pills . . . and I dropped like 40 pounds in a month and a half . . . So he* [physician] *took me off of them, and I realized that I needed them.*" He had a prescription for Geodon, which he was able to refill and resume his medication regimen. His story was also characterized by his strong relationships with his girlfriend and his grandmother that he has maintained over the course of many years and many placements. Both his girlfriend and his grandmother are supportive of his medication use.

With a support system in place and the recent experience of being off medication and then resuming medication, this young man reports a strong motivation to continue medication treatment. His outlook on his future use of medication appears to be shaped by his understanding of his symptoms as a medical problem: *"Just like some people who have asthma, they take their inhaler and their medication for it. Same thing pretty much; just different situation."* He notes beneficial effects of the medication, saying, *"I don't really feel like I'm bipolar now. Like with my medicine, you know, I feel like a normal person."*

Ambivalent About Medication

Another type of medication narrative was characterized by ambivalence and an uncertain outlook on the future. Young people in this category described not

wanting or liking medication and reported feeling that medication did not work for them. In several instances, the young person described using street drugs instead of or in combination with their prescribed medications. Similar to those who were committed to medication treatment, contextual factors contributed to the ambivalent outlook, including lack of supportive others and a lack of prior positive experiences in treatment. Case example #2 illustrates this ambivalent outlook.

Case Example 2

Case 2 is a 19-year-old African American female living in her own apartment. She is unemployed and is worried about what will happen with her housing situation when her lease expires next month. She currently takes no medication, but reported past use of Wellbutrin, Celexa, trazadone, Risperdal, and Seroquel. She first started taking medications for emotional and behavioral problems at age 13 years, and last took medication at age 18 years. Her history includes involvement with publicly funded Medicaid mental health, child welfare, juvenile justice, and the public welfare system. She aged out of the foster care system and has become disengaged from services since leaving foster care, stating she does not know the specifics of where or how to get services.

She describes her disorder as bipolar and her symptoms as extreme irritability, but expresses ambivalence about the role of medications in treating her symptoms. She noted that she has stopped taking the medications because of the adverse effects but also expressed some positive opinions about medication:

> *I think for me it's been good and bad, because I don't feel like . . . The last medicine I was on was that trazodone and I was always irritable, like even more so now. So, the good thing is I'm not as irritable, but the bad thing is I don't get much sleep, so it's like a good and a bad coming with it* [being off medication].

Her treatment experiences during childhood while in the custody of the child welfare system were not particularly positive and she noted that she did not like that her care providers were *"putting me on medicines that I really didn't really want, and if I didn't take my medicine I got in trouble."* She reported an experience of finding a medication she thought was effective but did not like the adverse effects: *"I just didn't like the fact that it made me eat . . . Seroquel was like the perfect medicine, besides the weight thing."* One of her strategies for managing moods without medications has been using marijuana, but she has not found that this drug helps either.

She seemed to be actively searching for a solution that would help manage her moods, and reported receiving strong support from a sister and her girlfriend. Her hopes for treatment in the future centered on finding some type of formal treatment that worked to manage her symptoms. She concluded the

interview with a summary of her hopes for treatment: *"I just really want a therapist, a psychiatrist, and to figure out what med is right for me."*

No Interest in Medication

The third type of medication narrative—in which participants expressed no interest in continuing medications—was less prominent in our sample. Only one young person among the more densely coded cases had discontinued use of medications and stated no intention to resume using medication. He stated that he thought his problems had been more developmental than organic, and his intention to remain off of medications was in line with this belief. He identified having a support network that supported this decision as well as coping skills that helped him in dealing with everyday problems.

Case Example 3

Case 3 is a 20-year-old African American male who is living with a friend. He currently takes no medication, but reports having taken Ritalin, Concerta, Dexedrine, and Zoloft in the past. He first started taking psychotropic medication for emotional and behavioral problems at age 10 years, and took medication continuously from ages 10 to 14 years. His history includes involvement with publicly funded Medicaid mental health services, child welfare, special education, and juvenile justice systems. He has not used any mental health services since turning 18, and reported feeling that he has "grown out" of many of the problems that led him to service use during adolescence. He describes the developmental process that he attributes as the reason for his improved mental health status:

> *I feel it* [mental health problems] *stopped because I feel I have people I could talk to and I could let my feelings out, 'cause I used to just hold my feelings in and when I would get angry, just all explode at one time, but now that I've matured and I'm more comfortable with talking to people . . . I can express my feelings to people.*

He reports having a girlfriend and friends he can talk to as well as alternate coping skills such as playing basketball and listening to music.

His experiences in taking medication during his adolescence shaped his desire to discontinue that form of treatment when he got older: *"I felt like my mom was just, my parents were just sending me to therapy as an escape and then using the medicines as an escape just 'cause they didn't know how to deal with me."* He attributes the cause of his problems to spending a substantial amount of time alone, having no one to talk to, and not knowing how to express himself. As he grew older, he learned new skills that addressed the problems that he perceived caused his former difficulties. He commented that his current difficulties were not *"bad to where I need to go to a professional."* His key support comes from his

mother; although she encouraged him to get medication during childhood, she now supports his decision not to use services.

Discussion

This study assists in developing a better understanding of the medication perspectives of young adults who are transitioning to adulthood, and presents a unique analysis that is focused on young people with mood and emotional challenges who have been involved in public systems. Several key findings emerged that offer implications for practitioners who are seeking to support young adults who are trying to make sense of their medication treatment.

First, across both the thematic and narrative analyses, we found that a developmental approach to medication perspectives is fundamental. We identified four dimensions of medication effects that young people used to explain how they experienced medications; these dimensions are similar to those identified in prior research with both adolescents (Floersch et al., 2009) and adults (Bentley, 2010). Such research with adolescents has shown that families and peers play a significant role in shaping the young person's attitudes toward medications (Floersch et al., 2009), whereas in work with adults, Bentley (2010) found that medication use was "primarily an internal and individual experience" (p. 490). The statements of participants in our study were consistent with an individualized view in which young adults talked about their symptoms and their experiences with medication effects. However, the narratives also showed the importance of supportive others in relation to these views. As adolescents become young adults, they take on a different relationship with the medication, much as they take on a different relationship with their primary support system and the social service system. With increased autonomy, young adults need to develop their own investment in their service use narrative; in other words, this narrative must gradually become an internalized, individual experience that supports the treatment decisions they make. To have it otherwise would mean the young adult would forever remain dependent on external others to monitor and supervise medication or other mental health treatment. In short, the experience of taking medications involves more than a daily routine of "take this pill." Young adults talked about how the medications affected them in both positive and negative ways and across multiple dimensions; they described how these myriad effects contributed to their decisions to continue or discontinue medication as they took control over their treatment.

A second key finding was the importance of treatment experiences in shaping medication perspectives. Young people spoke of enduring a trial-and-error process in getting medications, but interpreted this process in different ways, which tended to be heavily influenced by their success in finding an effective medication. Making sense of this process was likely a direct result of what others have

described as the gap between the hoped for and the actual effects of the medication (Longhofer, Floersch, & Okypch, 2011). When young people found what they considered to be the right medication, they usually provided more positive comments about the trial-and-error process. For those who had yet to find the right medication, the trial-and-error process was often appraised negatively; they expressed frustration and reported feeling like a guinea pig. Psychiatrists and mental health professionals who support young adults through treatment need to be clear at the outset about the trial-and-error nature of psychiatric medication treatment. Ongoing discussions could assist young adults in managing this gap between the hoped for and the actual effects of their medication treatment, and potentially lead to greater investment in following treatment recommendations and problem solving when a medication does not work.

Participants also noted interactions with psychiatrists as a significant part of the experience of medication treatment. This finding is in line with prior research that has noted a positive association between a patient's trust in a provider and a patient's positive attitudes toward medication treatment (Davis-Berman & Pestello, 2008; Laurier, Lafortune, & Collin, 2010). Unfortunately, the current structure of treatment which allows psychiatrists only limited time with their patients likely contributes to a lack of trust in providers. A recent study with young adults found a key facilitator to their treatment participation was the availability of their psychiatrist (Delman, Clark, Eisen, & Parker 2014). The young adults in our study had much to offer as historians and as experts on their mental health; their views were in line with several recent studies that found young people want to be involved in collaborative approaches to treatment (Delman et al., 2014; Simmons, Hetrick, & Jorm, 2011). Approaches that facilitate mutual engagement of young people and psychiatrists in determining treatment such as shared decision making could assist in improving satisfaction and follow-through with treatment recommendations (Drake, Deegan, & Rapp, 2010). The components of the medication narrative we identified in this study may provide a foundation for shared decision making. Soliciting the young adults' views on the symptoms and diagnoses the medication is intended to treat, the medication effects, and the potential role of medications in the future provides a framework for dialogue and the open communication necessary for shared decision making.

As providers engage in these conversations with young people, it will be important to maintain a value-neutral approach that focuses on simply understanding the young person's medication narrative. In the current study, those who were committed to continuing medication treatment often attributed their symptoms to a biological cause such as a chemical imbalance. The biochemical perspective was widely promoted when psychiatric medications became popular in the early 1990s (Whitaker, 2005); however, the biological mechanisms that

result in mental health symptoms are still poorly understood (U.S. Department of Health and Human Services, 1999) and it is not clear that chemical imbalances are the cause of mental health disorders. Those who experience symptom relief might decide that if a medication is working, then there must be a biological explanation (Cohen & Hughes, 2011) rather than starting with the belief in an underlying chemical imbalance. The biological explanation provides insight into how young adults may make sense of their experience, but this explanation should not be regarded as the correct explanation or superior to other explanations: it is simply the internalized narrative that some youth have come to own.

Another finding of our study was that participants often described coming to an understanding of their need for medication through comparisons of their symptoms when on and off the medications. However, psychiatric medications produce changes in the brain that may result in withdrawal symptoms when medications are abruptly discontinued (Whitaker, 2005); therefore, the experiences of exacerbated symptoms when medications were suddenly stopped might also be an iatrogenic effect of the medication treatment. This possibility also underscores the importance of privileging the young person's internalized medication service use narrative before complicating that narrative with external (e.g., psychiatry, social worker, parent, peer, teacher) medication narratives. Ideally, through understanding perspectives and narratives about medications, providers can deliver mental health treatments that make sense to the young people who receive those interventions.

Strengths and Limitations

Our study presents perspectives on medication use from a unique group of young adults with histories of formal diagnoses of mood disorders. Because it is a qualitative sample recruited using purposive sampling in one state, the results are not generalizable to all young people who have transitioned out of systems of care and/or have received a diagnosis of a mood disorder. Moreover, our study sample was a specific subset of young people who had histories of medication use and current indication of mental health need, and did not include the experiences of young people who took medications while in systems but who have had no mental health problems since leaving care. The interview guide was designed to elicit narratives about mental health service use broadly, so questions were not specific to medications. As such, the study findings might be biased toward presenting the views of young people who felt strongly about their medication use. However, the fact that young people presented their views about medication use within broader narratives, could be considered a strength because the narratives contain reflections about medications relative to the individual's everyday functioning and transition to adulthood. A final limitation that should be considered in interpreting the comments made by these young people is the effect of psychiatric medica-

tion treatment itself. Psychiatric medications affect the brain and have been documented to produce significant changes in mood and attention (Healy & Farquhar, 1998), which might have influenced the type and quality of the information provided by young people taking these medications.

Conclusion

Young adults who have exited public systems of care with mood and emotional challenges are a particularly vulnerable group with high needs and limited resources. This study provides insight into their perspectives on psychiatric medication and suggests some potential avenues for improving interventions. The findings highlight the need to use a developmental approach in supporting young adults' decisions about treatments, which has been discussed as being increasingly influenced by the attitudes toward and perceptions of illness held by the young adults (Munson et al., 2009). Clinicians can play a key role in helping young people to understand the trial-and-error process of medication treatment and to help find a treatment that works for and makes sense to them. Models such as shared decision making can promote an atmosphere in which young people work in greater partnership with their psychiatrists, and thereby feel respected, listened to, and involved in their treatment. Approaches that honor young adults' thoughts and emotions and engage them in making sense of their treatment, hold promise for promoting greater engagement and enhancing self-determination.

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