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The Subjective Experience of Youth Psychotropic Treatment

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Summary

The psychotropic treatment of youth is increasing dramatically. This article examines child and adolescent psychopharmacological research and argues that social work practice and research must examine the complex relationships, social and psychological, in youth pharmacologic treatment. Regarding identity formation, this article explores the developmental consequences when youth adopt an illness narrative to make sense of everyday medication treatment. A conceptual framework for mapping the socio-cultural context of youth medication management is outlined. In the conclusion, youth psychotropic treatment is connected to a perplexing 'interpretive gap,' which highlights the subjective quality of medication treatment.

Keywords

Child; adolescent; psychotropic treatment; illness identity; medication management

Introduction

The psychotropic treatment of children and adolescents, ages 4 to 18, increased dramatically (some estimate by 3-fold) during the last decade of the twentieth century. This increase marked a new era in treatment of early onset psychiatric disorders (Gadow, 1997; Greenhill, 1998; Jensen, Bhatara, & Vitiello, 1999; Minde, 1998; Schirm, Tobi & Zito, 2001; Safer, Zito, & Fine, 1996; Zito, Safer, & dosReis, 2000; Zito, Safer, & dosReis, 2002). The central aim of this article is to review child and adolescent psychopharmacological research and argue that social work practice and research must examine the complex relationships, social and psychological, in youth pharmacologic treatment. By focusing on identity and the meaning of medication—issues that psychotropic treatment serves up to social work—practice, research, and ethical questions are examined, especially the socio-cultural context of medication management. In the conclusion, between the 'desired' and the 'actual' effects of psychotropic intervention, an "interpretive gap" is identified. This gap, it is argued, will always be present and will require some type of clinical, therapeutic, or personal interpretation. Consequently, involving youth as full partners in psychotropic treatment means listening and responding to how they make sense (i.e., interpret) of medication experience.

1990s: The Decade of the Child's Brain?

In 1990, George Bush declared a decade of the brain. And though he meant this mandate to cover the sweep of human development and neuroscience, in retrospect it would seem that the child's brain was the target. In his extensive review of three decades of pediatric psychopharmacoevidence, Gadow (1997) documents a steady rise in the percentage of youth receiving medication. Safer and Krager (1988), extrapolating from Maryland data,

estimate that nationwide 1.6 million school children were medicated for “hyperactive/inattentive symptoms.” Zito et al. (2000) report a 65% increase (1988 to 1994) in the number of prescriptions written each year for preschool children; antidepressant use among youths 2-19 increased 2.9-fold (Zito, Safer, & dosReis, 2003; Zito & Safer, 2001). “The psychotropic medication visits of children and adolescents (younger than 18 years) increased significantly from 1.10 million in 1985 to 3.73 million visits in 1993 and 1994; as a proportion of all psychotropic medication visits, they increased from 3.4% to 8.2%, respectively” (Pincus, Tanielian, & Marcus, 1998, p. 528). Of youth, as many as 50% of all psychiatric inpatients, and as many as one-third of psychiatric outpatients are prescribed some type of antipsychotic (Findling, Schulz & Reed, 1998, p. 1207). Antipsychotic medication is often prescribed for adolescent inpatients, even in the absence of psychotic disorder (Zito, Craig, & Wanderling, 1994). And for outpatients, the three most prescribed medications are psychostimulants, antidepressants, and antipsychotics (Kaplan, Simms, & Busner, 1994).

Prominent psychopharmacological researchers observe with regret that increased use has not produced important areas of new knowledge related to safety and adverse events (Findling & Dogin, 1998; Greenhill, Vitiello, & Abikoff, 2001; Jensen et al., 1999; Riddle, Kastelic, & Frosch, 2001; Vitiello, 2001; Zito & Safer 2001; Zito et al., 2003). A central concern is the uncertainty about how medication influences physical development (Greenhill et al., 2001; Jensen et al., 1999; Riddle et al., 2001; Tosyali & Greenhill, 1998; Vitiello, 1998). Some have argued that what “is specific to psychopharmacology is that the target organ, the brain, undergoes dramatic developmental changes which involve, among others, the very neurotransmitter systems upon which psychotropic drugs act” (Vitiello, 1998, p. 582). And kids are particularly vulnerable to age-dependent toxicities (Greenhill et al., 2001, p. 877). Although paucity of empirical data has made youth research and treatment complicated, it has not deterred practitioners; findings from adult research are applied to children and adolescents. Indeed, estimates are that 75% of prescriptions are off-label (Zito & Safer, 2001), that is, never tested on youth. By reminding the larger community that children are not small adults, off-label use patterns have sent many advocates, clinicians, and researchers clamoring for child-centered efficacy tests (Emslie, Walkup, & Pliszka, 1999; Riddle et al., 2001). Although youth research is made thorny by unique ethical and informed consent issues, it is argued that these difficulties should not justify blind, off-label prescribing (Ryan, Bhatara, & Perel, 1999; Tosyali & Greenhill, 1998).

The upswing in youth psychotropic treatment has led researchers to speculate that “a number of forces working in concert have spurred changes in research perspectives and clinical practices that led to this recent boom” (Riddle et al., 2001, p. 73). Increased government funding and FDA regulatory (in 1994) adjustments have contributed to expanded child research (Vitiello, 2001; Walkup, Cruz, & Kane, 1998). Noteworthy for social work is the perception that the trend is likely due to a “growing acceptance of a disease model of childhood psychopathology” (Riddle et al., 2001, p. 73; see also, Gadow [1997] and Wilens [1999]). It has been shown that illness identities among adult users of mental health services have been associated with biological explanations of depression (Karp, 1996). How might these findings relate to childhood mental illness and the possibility of the formation of youth illness identities?

Child and Adolescent Development, Identity, and Psychotropic Treatment

Research on development has understandably focused on adverse biological effects (e.g., brain, growth, weight gain, high blood pressure, and early onset of puberty). And it is doubtful that anyone would question our obligation to keep children physically safe (Vitiello, 1998). Yet, however adverse the potential biological effects, there are equally important concerns about psychological and cultural ones. “Besides keeping an open mind and being clinically vigilant, the key to successful treatment often lies in a good understanding of developmental issues and

how these can affect the timing and efficacy of psychopharmacological and behavioral treatments” (Tosayali & Greenhill, 1998, p. 1031). At some point a child confronts medicine for the first time and responding to medication itself is not extraordinary; children are typically introduced to physical medicine before mental health. With physical illness, however, the scientific community has explored how youth respond to treatment and medication, especially invasive interventions (Anderson, Ho, & Brackett, 1997; Chernoff, Ireys & DeVet, 2002; Glasgow & Anderson, 1995; Gudas, Koocher, & Wypij, 1991; Horwitz, Leaf & Leventhal, 1998; Ivers-Landis & Drotar, 2000). We have not, however, studied the myriad ways youth make sense of mental health medications. Is “*take this and it will make your fever go away*” equivalent to “*take this and it will calm and slow you down?*”

For example, how do we interpret a teenager account of medication effects (desired or actual) when their developmental predisposition, separation and autonomy from parents, poses unique challenges for interpreting their resistance to parental and physician desire for medication use (Cromer & Tarnowski, 1989; Ghaziuddin, King, & Hovey, 1999; Harrop & Trower, 2001; Rappaport & Chubinsky, 2000)? Indeed, noncompliance may not at all express a need for autonomy; it may instead be the expression of a wish to avoid side effects. We cannot know how to interpret, however, unless we take seriously the myriad ways developmental issues intermingle with youth pharmacologic treatment.

For example, maturation and development make diagnosis, the first step in the psychotropic treatment process, unusually difficult (Jensen, 1998; Vitiello, 2001). As a rough measure of this ambiguity, Zito and Safer's (2001, p. 1123) chart review showed that 55% had one diagnosis, 27% had two diagnoses, and 18% had three to ten diagnoses. Thuppall, Carlson, and Sprafkin (2002) believe that developmental issues make youth unreliable informants, especially when mania symptoms are elicited. Because “some symptoms are visible to caregivers and some are not” (Thuppall et al., 2002, p. 27) the child's input is *necessary* for accurate diagnosis. Other symptoms are difficult to clarify in structured interviews and comparative developmental norms for key symptoms are not readily available. Geller, Zimmerman and William (2002a) claim there are few pediatric equivalents of adult mania symptoms (e.g., like maxed out credit cards and fourth marriages). They write that “unlike manic adults, children gave concrete answers to describe their racing thoughts. Examples are: A girl pointed to the middle of her forehead and stated, ‘I need a stoplight up there’” (2002a, p. 7). Indeed, Geller et al. are alone in utilizing youth specific symptoms when establishing a diagnosis, which, they argue, if routinely practiced would decrease diagnostic unreliability. The child's maturation level will also determine how concrete or abstract their symptom perceptions will be; first, it is important to assess the child's maturation and developmental status; second, to confirm their diagnosis; and third, to prescribe their medication. In sum, Geller et al. (2002a; Geller, Zimmerman, & William, 2002b) demonstrate that converting adult diagnostic markers to youth assessment requires researcher and practitioner *phenomenological* interpretation of youth symptomatology and experience.

Yet, in child and adolescent mental health, as in medicine overall, the necessary first step for a prescription is a precise diagnosis. With a diagnosis it can be argued that we are treating a disorder. Absent a diagnosis, the aim may be to “control behavior, as in the use of antipsychotics to control aggression among nonpsychotic children” (see Kaplan et al., 1994). For preschoolers, in particular, Vitiello (2001) believes there is a strong tendency to treat symptoms and behavior because diagnosable pathology is rare. In short, youth prescribed psychotropic medications are not likely to be, *in the sense of a diagnosis*, ‘psychotic.’ In those cases where a diagnosable disorder does not exist—or even where it is ambiguous—how do youth experience the link between the prescription (e.g., antipsychotic, antidepressant, psychostimulant) and the target symptom? If a child is not given a diagnosis for psychosis, how do they make sense of the need for antipsychotic medication? Do they use illness identities to rationalize medication use? We

will not have the answers to these and many related questions if we do not study youth subjective experience.

What does it mean for a child or adolescent sense of an emerging self (and identity) if in “fact new models for conceptualizing childhood psychiatric disorders as illnesses clearly facilitates the use of psychotropic medications in the pediatric population” (Walkup et al., 1998, p. 1267)? Phenomenological research has established the formation of an illness identity among adult long-term users of health services and medication (Conrad, 1985; Charmaz, 1990; Karp, 1996; Kleinman, 1988; Riessman, 1990). It is argued that illness becomes part of the self: “I am diabetic,” for example. In cases of adult schizophrenia, Sue Estroff (1993) argues that becoming a ‘schizophrenic’ denotes a brain *and* emotional disorder; physical illness, on the other hand, marks only one aspect of our existence. Floersch (2002) argued that community support advocates joined an illness identity with a biological explanation to help facilitate hospital closure and the subsequent transfer of monies to community clinics. And although Deborah Stone (1984) effectively argues that receiving state and federal monies requires acceptance of the state’s legal category of disability, the use of an illness narrative is more than a political-economic imperative. Apparently, narratives help adults meaningfully integrate illness experience (Kleinman, 1988). David Karp (1996), for example, has demonstrated that adults are active agents in making sense of medication. He concludes 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” (Karp, 1996, p. 102). Karp argues that the acceptance of depression as a disease (“I am depressed”) is often a predictor of positive medication compliance. Would this also be true for children and adolescents?

Are illness identities forming among youth under conditions of psychotropic treatment? Clarke’s (1997) qualitative study of 20 ADHD diagnosed children between the ages of 6 and 14, a singular exception in this literature and the only clear study of children’s subjective experience, found that five revealed that they experienced themselves being sick in some way, either physically or mentally, because of having ADHD (Clarke, 1997, p. 76). Since we have not conducted phenomenological studies of youth, we do not know the extent to which they use illness identities to make medication treatment meaningful (as an exception, see Henker & Whalen, 1980). If, as most developmental theory suggests, identity formation is part of the work of early and late adolescence, will an illness identity serve the same interpretive function for youth as it apparently does for adults? What does it mean for an emerging ‘self’ to be medicated? And finally, perhaps no illness identity forms, in which case what kind of explanatory schemes do youth utilize to rationalize the need for medication?

Why Include Youth Subjective Experience in Practice and Research?

Research on the subjective experience of adult psychiatric disorder and medication has resulted in important findings. Phenomenological research has provided insights into the myriad ways adult symptoms are expressed (Leff & Vaughn, 1985; Jenkins, 1991; Jenkins & Karno, 1992; Jenkins, 1994; Jenkins, 1997). Culturally sensitive assessment tools depend on subjective data to create valid diagnoses (Canino, Canino, & Arroyo, 1998; Kirmayer, 1998; Jenkins, 1998, Lewis-Fernandez, 1998; Manson & Kleinman, 1998). Most important, by investigating how illness and treatment experience is shaped by the active engagement of the person, we have learned the importance of differentiating between ‘the ill’ self and the effects of the illness on the self (Conrad, 1990; Kleinman, 1988; Strauss, 1989).

Although practitioners and researchers are aware of the problem of subjectivity, we have little understanding of how youth interpret experiences of the doctor’s office, the researcher’s clinical trial, and other medication experiences. Riddle et al. (2001), for example, list the “subjective distress associated with the symptoms” (p. 76) as one among three critical components for

competent assessment of youth psychopathology. Still, researchers have reported that youth are often ridiculed for taking medication and often embarrassed or self-conscious about anti-psychotic (zombie-like) side effects (Findling & Dogin, 1998; Findling et al., 1998; Rappaport & Chubinsky, 2000). Exacerbating this is the normal, self-conscious, adolescent preoccupation with body-image and related feelings. And Clarke discovered that the most common fear of school-age (ages 8-12) children on Ritalin “was the fear of possible harm to the body” (Clarke, 1997, p. 94). “Psychoanalytic theories of development underscore the normal childhood fear of body damage and harm” (Tyson & Tyson, 1990, pp. 216-217). For example, Rappaport and Chubinsky report that

even if the clinician has reassured the parents, children are also often apprehensive about taking medication and commonly believe that this is a final proof that they are defective. Although they may not initially express these thoughts, many children will at some point call themselves crazy, bad, or stupid as an explanation for why they take medicine. Others may fear that they are brain damaged. One 10-year-old boy who had both attentional problems and depression was seen in play therapy and initially did well on medication. He then repeatedly enacted, in play, a doctor poisoning his patient. (Rappaport & Chubinsky, 2000, p. 1199)

How do we assist in understanding the fantasies and fears generated by psychotropic treatment (Shapiro, 1996)? Do we even ask?

About the nature of personal narratives in general and their importance to social science research, Ochs and Capps succinctly state that, “we come to know ourselves as we use narrative to apprehend experiences and navigate relationships with others. The inseparability of narrative and self is grounded in the phenomenological assumption that entities are given meaning through being experienced and the notion that narrative is an essential resource in the struggle to bring experiences to conscious awareness” (Ochs & Capps, 1996, p. 21). Narratives give rise, create, and build coherent and multiple understandings of our ‘being’ in the world. Thus, narratives have point-of-view and temporal features. And both features are relevant to youth medication research.

First, because the diagnosis of early childhood disorders is difficult, treatment of “aggression, impulsiveness, mood instability, anxiety, and sleep disturbances are the most common reasons for clinical referral and treatment. ... However, the immediate clinical appeal to this approach is counteracted by the lack of evidence that these symptoms have the same *meaning*” [my emphasis] (Vitiello, 2001, p. 985). Because there is no plasma level test for assessing optimal psychostimulant dosage (Findling & Dogin, 1998), moreover, the need for monitoring desired effects is left to the ‘*interpretation*’ of behaviors or illness symptoms. It is speculated that youth psychotropic narratives are dependent on how mental health providers, family, and teachers rationalize the need for medications. Rappaport and Chubinsky also believe that

in trying to understand specific meanings to a child, the psychiatrist may find that a child with a history of seizure disorder is more likely to see the need for medication as evidence of brain damage and a child with a learning disability as confirmation that he is stupid. (Rappaport & Chubinsky, 2000, p. 1199)

Second, the temporal feature of narrative complements basic development theory, which suggests that as youth apprehend past and present experience they gain a coherent sense of ‘me.’ But this sense of self changes rapidly with age; the school-age sensibility of self is not the same as an adolescent. And the tension between a coherent and changing sense of self produces narrative activity that “seeks to bridge a self that felt and acted in the past, a self that feels and acts in the present, and an anticipated or hypothetical self that is projected to feel and act in some as yet unrealized moment” (Ochs & Capps, 1996, p. 29). What is the school-age child's past experience with psychotropics, present experience, and future anticipated

experience? Clarke, for example, found that 11 of 20 youth feared becoming dependent on medication; she also found that their feelings of dependency increased as their positive acceptance of psychostimulants decreased (Clarke, 1997, pp. 77-80).

Investigating point-of-view and temporal features of narrative would help us understand differences and similarities in medication experience among youth and help to establish clinical and psychosocial community-based standards, which at present seem only concerned with prescription type and dosage amounts (Pliszka, Greenhill, & Crismon, 2000). Moreover, “longitudinal cohort studies would permit the study of developmental changes” (Greenhill et al., 2001; Werry, McClellan, & Chard, 1991; Zito & Safer, 2001) and the myriad ways the youthful self variously takes in the experience of *being* medicated.

The Socio-Cultural Context: Managing Youth Psychiatric Disorder and Medications

Development and clinical theorists (Furman, 2001) and medication compliance researchers (Chewning & Sleath, 1996; Chewning & Schommer, 1996; Chewning, 1997; Sleath, 1996; Sleath, Svarstad, & Roter, 1997) concur that the more responsibility patients assume for everyday self-care and self-monitoring, the less likely they will resist medical treatment. Brown, Borden and Wynne (1988) found that children with higher perceived self-control have higher rates of compliance. In one psychostimulant compliance study, sixty-five percent of the children avoided taking medication (Sleator, Ullman, & Von Neumann, 1982). Clark concluded that an ADHD child's “strong desire for self-reliance is irreconcilable” to attributions linking pills to improvement (Clark, 1997, p. 97). In a study to increase compliance, Bastiaens speculates that adolescent feelings and ideas about medication should be directly examined and modified because increasing information about psychotropic treatment alone was not enough to positively influence compliance (Bastiaens, 1995). How would a practitioner modify attitudes and feelings without a simultaneous strategy to understand how youth monitor and make sense of medications? Is self-monitoring encouraged, or do parents, teachers, and doctors monitor *for* the child?

Youth experience of psychotropic medication does not occur outside of social context. Whether the *pill* or the *self* is attributed the power to produce change is largely dependent on the socio-cultural context of medication management. Even for adults, the consumption of medication is not a singular biological event. Longhofer, Floersch, and Jenkins (2003), for example, have identified five elements of an adult medication experience: (1) presenting problem or symptoms, (2) psychiatric diagnosis and prescription assessment, (3) access to or delivery of medications, (4) monitoring for compliance and effect, and (5) reporting. These elements, in turn, unfold in a grid of social relations (for a similar argument, see Cohen, 2002); and clinical trial research is usually not concerned with the community noise of *in vivo* medication practice (Biederman, Mick, & Bostic, 1998; Gadow, 1997; Hoagwood & Olin, 2002; Hohmann & Shear, 2002; Riddle et al., 2001; Zito & Safer, 2001). In short, *who* does *what* and *why* matters to youth under conditions of psychotropic treatment.

A grid of relations produces the boundaries for *interpretive* contexts within which biologic effects become psychologically and sociologically *meaningful* treatment experiences. For instance, because distinguishing ADHD symptoms from mania is difficult, Geller et al. (2002b) speculate that “bipolar children may be viewed by their community practitioner gatekeepers as complicated ADHD cases. And as a result, they may have been more likely to be referred to pediatric or child psychiatry sites” (p. 23). Therefore, it is in the management of medication treatments that interpretive contexts present special problems, and it is likely that the management context shapes the quality and types of narratives generated by treatment conditions. Zito et al. (2000) found disparities in prevalence data between two Medicaid school-

age populations, suggesting that “the cultural values that underlie families' decisions to accept or reject medication for behavioral or mental disorders is one reason for the difference” (p. 1029).

For youth, parental involvement in medication experience is a key grid component that must be addressed in research and practice (Clarke, 1997). Parents can feel relieved “when a physician suggests medication; it validates their concerns about the serious nature of their child's problems” (Rappaport & Chubinsky, 2000, p. 1198). Those who refuse to have children medicated, moreover, may have conflict with teachers and school administrators. Firestone (1982) found that only 10% of parents informed their doctor of discontinuation. In clinical work, Erna Furman has demonstrated that parents must have the ability to first “feel with” the child in order for the child to learn self-care abilities (Furman, 2001). Thus, youth capacity for self-monitoring and self-reporting desired and actual effects of medication is likely to depend on the parent's (ongoing) investment in self-care capacity. It seems plausible that medication self-reporting is dependent on the child's ability to observe and report on—bodily, feeling, thinking, and behavioral—experiences that become tagged to medication. If the child cannot observe and monitor, then a parent or substitute does the management work *for* them.

Typically, clinical-trial psychopharmacology does not correlate findings to the social conditions influencing medication experience (Hohmann & Shear, 2002). Nor has it investigated the myriad ways each of the five elements necessarily combine in a particular social grid (i.e., children, parents, teachers, doctors, etc.) to constitute a holistic (i.e., biological, psychological, and social) and meaningful medication narrative. But we should not expect clinical trial investigations to do such work. Instead, it is the work of social science to understand how technological interventions become socially meaningful, cultural phenomena. In the grid constituting youth medication interventions, under what circumstances do participants (e.g., parents, teachers, doctors, peers) share interpretations about intervention and effects?

Understanding *youth experience* must be seen through the grid of relations that mediates the five elements of medication management (Longhofer et al., 2003). Investigating patients' social grid of medication management reveals, for those not self-monitoring, who in the grid monitors *for* them. When managers, for example, stepped forward to report *for* the patient (Floersch, 2002), was this to be coded as patient resistance to the medication regimen? Or, was the patient simply not able to self-monitor? These questions cannot be answered with methods that fail to account for the patient's subjective experience of medication. It is crucial, then, to youth research and practice that anthropological and phenomenological methods take account of the child or adolescent point of view. Children who experience medication management as controlling—or forced—may not comply with regimen requirements. Those who allow others to monitor *for* them may be resisting the regimen. If an adolescent is prescribed an antipsychotic for aggression and not for a psychotic diagnosis, does this lead to different experience and relations in the grid of management? It is speculated that youth have many participants in their grid (i.e., parents, teachers, psychiatrists, pediatricians, social workers, friends, and siblings) but how participants negotiate everyday monitoring and reporting has not been studied. And unlike adults, children are more dependent on family; thus the youth grid of medication management will likely produce a distinctive experience.

Moreover, Floersch, in *Meds, Money, and Manners* (2002), discovered that case managers utilized psychopharmacology and practical (or situated) knowledge (e.g., “has the medication kicked in,” and “it clears the mind”) to rationalize the need for medication. These practical understandings performed essential community work; it was not, however, a part of manager awareness. For example, managers constantly read and coded patient actions, feelings, and thoughts in order to draw conclusions about a medication's power to produce self-directed

behavior. As one imagines the blood circulating chemicals to the brain, managers worked in the grid of social relations to circulate meanings about what it meant to their clients to be medicated. To a manager, the slightest change in walk, tone of voice, and daily routine could signify the efficacy of medication. Floersch concluded that manager's medication effect interpretations would not be so difficult: (1) if drugs always produced the desired effect, and (2) if patients, understood, with the same understanding of practitioners, the relationships between medication and effects (2002, p. 178). Like managers' practical medical language, it is speculated that parents and adolescents also use a practical language, while pediatricians use a medical lexicon and psychiatrists use a medical-pharmacological language to rationalize youth medication experience. If youth have many more participants in their medication grid, then meanings will likely proliferate more for youth than in adult socio-cultural contexts. What does it mean to different grid participants to have youth behavior, feeling, or thought (i.e., target symptoms) medicated? And do grid participants rationalize the aim of mental health medication with psychopharmacological or with practical knowledge? Youth practical understandings of medication may have large influences upon outcomes. Adult research suggests that illness identities function to produce compliance, for example. For an adolescent who does not self-identify as biologically ill (with the disease of schizophrenia, for example), how do they rationalize the need for medication? Perhaps, youth compliance is dependent on who in the social grid of medication management rationalizes the need; for an adolescent, a peer may be more important than a parent, psychiatrist, or case manager.

And finally, social scientists need to study youth subjective experience and we need to map the thematic narratives they employ to make medication utilization meaningful. While on medication, are there themes of increased mastery (Clarke, 1997) or self-esteem (Frankel, Cantwell, & Myatt, 1999)? Are there themes of sickness? How about bad and good medicated feelings, and feelings of being different (stigma) from other non-medicated peers? Findling and Dogin (1998, p. 45) estimate that 30% of psychostimulant treatment fails, thus in those cases, how do youth experience a medication failure? It is unclear what narrative themes are likely to emerge, but our understandings of adult identity, illness, and management narratives are the likely sites for beginning youth research. A consequence of not studying youth medication experience is the mere adaptation of adult understandings and interpretations and this could be as problematic to the emotional, social, and cognitive development of youth as off-label prescription is to their physical health.

Conclusion

No matter how chemically fine-tuned psychotropic medications become through the billions that will surely be spent toward their refinement, we will always need to interpret their effects because they are first and foremost a part of lived experience. The gap between the 'desired' effect of medication and the 'actual'—clouded, of course, by unintended side effects—will never completely close. Indeed even the smallest gap requires us to make meaning of how medicines feel in the body. And only the person consuming the medication can make it a meaningful experience. Thus, in the distance between the desired and actual psychotropic effects there will always remain a phenomenological gap that cannot be bridged by the neurotransmitters that chemicals seek to affect; neurotransmitters do not have the power to assign meaning; however, the properties of social and psychological entities do possess these emergent powers (Sayer, 2000).

Social work is proud about the professional emphasis placed on starting where the client is. This practice axiom protects the valued principle of self-determination. At the very least, self-determination means asking youth about their experience and it means making the experience of taking medication a part of any clinical encounter that involves psychotropic treatment. Self-monitoring and self-reporting in medication management are the heart of self-determination;

in short, we need clinical theory and methods for assisting youth medication experience. Once a song, a color, a pet, or a smell become part of a child's inner world, we would not abruptly take these away or add new ones without carefully imagining their effects. Medications become meaningful to youth. Yet, in the practical search for the right medication and dosage, the regimen can change as often as the weather. Constant changes are not about children who cannot be helped. Rather, perhaps it is about a socio-cultural system of psychotropic treatment that displaces onto the child the uncertainty parents, practitioners, doctors, and teachers feel when they acknowledge that a medication's desired effect has not been *actualized* in the child. Once youth have tried medication, then they and others in their social grid will make "effect" interpretations (Floersch, 2002, pp. 167-174). In sum, the phenomenological reality of youth psychotropic experience—the gap between desired and actual effects—must be addressed in our research and practice. Perhaps, the decade of the child's brain is behind us and now we can only hope that research and clinical practice will catch up and begin to interpret youth psychotropic experience as part of socio-cultural (i.e., medication management) and therapeutic relationships.

References

- Anderson B, Ho J, Brackett J, Finkelstein D, Laffel L. Parental involvement in diabetes management tasks: Relationships to blood glucose monitoring adherence and metabolic control in young adolescents with insulin-dependent diabetes mellitus. *Journal of Pediatrics* 1997;130:257–265. [PubMed: 9042129]
- Bastiaens L. Compliance with pharmacotherapy in adolescents: Effects of patients' and parents' knowledge and attitudes toward treatment. *Journal of Child and Adolescent Psychopharmacology* 1995;5(1):39–48.
- Biederman J, Mick E, Bostic JQ, Prince J, Daly J, Wilens TE, Spencer T, Garcia-Jetton J, Russell R, Wozniak J, Faraone SV. The naturalistic course of pharmacologic treatment of children with manic like symptoms: A systematic chart review. *Journal of Clinical Psychiatry* 1998;59(Nov):628–37. [PubMed: 9862614]
- Brown RT, Borden KA, Wynne ME, Spunt AL, Clingerman SR. Patterns of compliance in a treatment program for children with attention deficit disorder. *Journal of Compliance in Health Care* 1988;3(1): 23–39.
- Canino I, Canino G, Arroyo W. Cultural considerations for childhood disorders: How much was included in DSM-IV? *Transcultural Psychiatry* 1998;35:343–356.
- Charmaz K. Discovering chronic illness: Using Grounded Theory. *Social Science Medicine* 1990;30(11): 1161–1172. [PubMed: 2360052]
- Chernoff RG, Ireys HT, DeVet KA, Young KJ. A randomized, controlled trial of a community-based support program for families of children with chronic illness: Pediatric outcomes. *Archives of Pediatric Adolescent Medicine* 2002;156:533–539.
- Chewning B. Patient involvement in pharmaceutical care: A conceptual framework. *American Journal of Pharmaceutical Education* 1997;61(4):394–401.
- Chewning B, Schommer JC. Increasing clients' knowledge of community pharmacists' roles. *Pharmaceutical Research* 1996;13(9):1299–1304. [PubMed: 8893265]
- Chewning B, Sleath B. Medication decision-making and management: A client-centered model. *Social Science & Medicine* 1996;42(3):389–398. [PubMed: 8658233]
- Clarke, CH. Ph.D dissertation. Loyola University Chicago, Department of Social Work; 1997. An exploratory study of the meaning of prescription medication to children diagnosed with attention deficit hyperactivity disorder.
- Cohen D. Research on the drug treatment of schizophrenia: A critical appraisal and implications for social work education. *Journal of Social Work Education* 2002;38(2):217–239.
- Conrad P. Qualitative research on chronic illness: A commentary on method and conceptual development. *Social Science Medicine* 1990;30(11):1257–1263. [PubMed: 2360060]
- Conrad P. The meaning of medications: Another look at compliance. *Social Science Medicine* 1985;20:29–37. [PubMed: 3975668]

- Cromer BA, Tarnowski KJ. Noncompliance in adolescence: A review. *Developmental Behavioral Pediatrics* 1989;10(4):207–215.
- Emslie GJ, Walkup JT, Pliszka SR, Ernst M. Nontricyclic antidepressants: Current trends in children and adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry* 1999;38(5):517–528. [PubMed: 10230183]
- Estroff, Su. Identity, Disability, and Schizophrenia: The Problem of Chronicity. In: Lindenbaum, S.; Lock, Margaret, editors. *Knowledge, Power, & Practice*. Berkeley: University of California Press; 1993. p. 247–286.
- Findling RL, Dogin JW. Psychopharmacology of ADHD: Children and adolescents. *Journal of Clinical Psychiatry* 1998;59:42–49. [PubMed: 9680052]
- Findling RL, Schulz SC, Reed MD, Blumer JL. The antipsychotics—A pediatric perspective. *Pediatric Clinics of North America* 1998;45(5):1205–1232. [PubMed: 9884683]
- Firestone P. Factors associated with children's adherence to stimulant medication. *American Journal of Orthopsychiatry* 1982;52:447–457. [PubMed: 7114173]
- Floersch, J. *Meds, money, and manners: The case management of severe mental illness*. New York: Columbia University Press; 2002.
- Frankel F, Cantwell DP, Myatt R, Feinberg DT. Do stimulants improve self-esteem in children with ADHD and peer problems? *Journal of Child and Adolescent Psychopharmacology* 1999;9(3):185–194. [PubMed: 10521011]
- Furman, E. *On being and having a mother*. International Universities Press; 2001.
- Gadow K. An overview of three decades of research in pediatric psychopharmacology. *Journal of Child and Adolescent Psychopharmacology* 1997;7(4):219–236. [PubMed: 9542694]
- Geller B, Zimerman B, Williams M, DelBello MP, Bolhofner K, Craney JLP, Frazier J, Beringer L, Nickelsburg MJ. DSM-IV mania symptoms in a prepubertal and early adolescent bipolar phenotype compared to attention-deficit hyperactive and normal controls. *Journal of Child and Adolescent Psychopharmacology* 2002b;12(1):11–25. [PubMed: 12014591]
- Geller B, Zimerman B, Williams M, DelBello MP, Frazier J, Beringer L. Phenomenology of prepubertal and early adolescent bipolar disorder: Examples of elated mood, grandiose behaviors, decreased need for sleep, racing thoughts, and hypersexuality. *Journal of Child and Adolescent Psychopharmacology* 2002a;12(1):3–9. [PubMed: 12014593]
- Ghaziuddin N, King CA, Hovey JD, Zaccagnini J, Ghaziuddin M. Medication noncompliance in adolescents with psychiatric disorders. *Human Development* 1999;30(2):103–110.
- Glasgow RE, Anderson BJ. Future directions for research on pediatric chronic disease management: Lessons from diabetes. *Journal of Pediatric Psychology* 1995;20:389–402. [PubMed: 7666280]
- Greenhill LL. The use of psychotropic medication in preschoolers: Indications, safety, and efficacy. *Canadian Journal of Psychiatry-Revue Canadienne De Psychiatrie* 1998;43(6):576–581. [PubMed: 9729683]
- Greenhill LL, Vitiello B, Abikoff H, Levine J, March JS, Riddle MA, Capasso L, Cooper T, Davies M, Fisher P, Findling RL, Fried J, Labellarte M, McCracken J, McMahon DJ, Robinson J, Skrobala AM, Scahill L, Walkup J, Zito J. Improving the methods for evaluating the safety of psychotropic medications in children and adolescents. *Current Therapeutic Research—Clinical and Experimental* 2001;62(12):873–884.
- Gudas LJ, Koocher GP, Wypij D. Perceptions of medical compliance in children and adolescents with cystic fibrosis. *Developmental and Behavioral Pediatrics* 1991;12:236–242.
- Harrop C, Trower P. Why does schizophrenia develop at late adolescence? *Clinical Psychology Review* 2001;21(2):241–266. [PubMed: 11293367]
- Henker, B.; Whalen, CK. The many messages of medication: Hyperactive children's perceptions and attributions. In: Salzinger, S.; Antrobus, J.; Glick, J., editors. *The ecosystem of sick child*. New York: Academic Press; 1980.
- Hoagwood K, Olin SS. The NIMH blueprint for change report: Research priorities in child and adolescent mental health. *The Journal of the American Academy of Child and Adolescent Psychiatry* 2002;41(7):760–767.
- Hohmann AA, Shear MK. Community-based intervention research: Coping with the noise of real life in study design. *American Journal of Psychiatry* 2002;159(2):201–207. [PubMed: 11823259]

- Horwitz SM, Leaf PJ, Leventhal JM. Identification of psychosocial problems in pediatric primary care: Do family attitudes make a difference? *Archives of Pediatrics and Adolescent Medicine* 1998;152:367–371. [PubMed: 9559713]
- Ivers-Landis, C.; Drotar, D. Parental and child knowledge of the treatment regimen for childhood chronic illnesses. In: Drotar, D., editor. *Promoting adherence to medical treatment in chronic childhood illness: Concepts, methods and interventions*. Mahwah, NJ: L. Erlbaum Assoc.; 2000. p. 259-282.
- Jenkins JH. Diagnostic criteria for schizophrenia and related psychotic disorders: Integration and suppression of cultural evidence in DSM-IV. *Transcultural Psychiatry* 1998;35:359–378.
- Jenkins JH. Subjective experience of persistent psychiatric disorder: Schizophrenia and depression among U.S. Latinos and Euro-Americans. *British Journal of Psychiatry* 1997;170:20–25. [PubMed: 9328489]
- Jenkins, JH. The psychocultural study of emotion and mental disorder. In: Bock, P., editor. *Handbook of psychological anthropology*. Westport, CT: Greenwood Publishers; 1994.
- Jenkins JH, Karno M. The meaning of ‘expressed emotion’: Theoretical issues raised by cross-cultural research. *American Journal of Psychiatry* 1992;149:9–21. [PubMed: 1728192]
- Jenkins JH. Anthropology, Expressed Emotion, and Schizophrenia. *Ethos* 1991;19(4):387–431.
- Jensen PS, Bhatara VS, Vitiello B, Hoagwood K, Feil M, Burke LB. Psychoactive medication prescribing practices for US children: Gaps between research and clinical practice. *Journal of the American Academy of Child and Adolescent Psychiatry* 1999;38(5):557–565. [PubMed: 10230187]
- Jensen PS. Ethical and pragmatic issues in the use of psychotropic agents in young children. *Canadian Journal of Psychiatry Revue Canadienne De Psychiatrie* 1998;43(Aug):585–588. [PubMed: 9729685]
- Kaplan SL, Simms RM, Busner J. Prescribing practices of outpatient child psychiatrists. *Journal of the American Academy of Child and Adolescent Psychiatry* 1994;33(1):35–44. [PubMed: 8138519]
- Karp, DA. *Speaking of sadness: Depression, disconnection, and the meanings of illness*. New York: Oxford University Press; 1996.
- Kirmayer LJ. Editorial: The fate of culture in DSM-IV. *Transcultural Psychiatry* 1998;35:339–342.
- Kleinman, A. *The illness narratives: Suffering, healing, and the human condition*. New York: Basic Books; 1988.
- Leff, J.; Vaughn, C., editors. *Expressed emotion in families*. New York: Guilford Press; 1985.
- Lewis-Fernandez R. A cultural critique of the DSM-IV dissociative disorders section. *Transcultural Psychiatry* 1998;35:387–400.
- Longhofer J, Floersch J, Jenkins JH. The Social Grid of Community Medication Management. *American Journal of Orthopsychiatry* 2003;73(1):24–34. [PubMed: 12674516]
- Manson S, Kleinman A. DSM-IV, culture and mood disorders: A critical reflection on recent progress. *Transcultural Psychiatry* 1998;35:377–386.
- Minde K. The use of psychotropic medication in preschoolers: Some recent developments. *Canadian Journal of Psychiatry-Revue Canadienne De Psychiatrie* 1998;43(6):571–575. [PubMed: 9729682]
- Ochs E, Capps L. Narrating the self. *Annual Review of Anthropology* 1996;25:19–43.
- Pincus HA, Tanielian TL, Marcus SC, Olfson M, Zarin DA, Thompson J, Zito JM. Prescribing trends in psychotropic medications: Primary care, psychiatry, and other medical specialties. *Journal of American Medical Association* 1998;279(7):526–531.
- Pliszka SR, Greenhill LL, Crismon ML, Sedillo A, Carlson C, Conners CK, McCracken JT, Swanson JM, Hughes CW, Llana ME, Lopez M, Toprac MG, Texas Consensus Conference, Panel On Medication Treatment of Childhood Attention-Deficit/Hyperactivity Disorder. The Texas children's medication algorithm project: Report of the Texas consensus conference panel on medication treatment of childhood attention-deficit/hyperactivity disorder. Part I. *Journal of the American Academy of Child and Adolescent Psychiatry* 2000;39(7):908–919. [PubMed: 10892234]
- Rappaport N, Chubinsky P. The meaning of psychotropic medications for children, adolescents, and their families. *Journal of American Academy of Child and Adolescent Psychiatry* 2000;39(9):1198–1200.
- Riddle MA, Kastelic EA, Frosch E. Pediatric psychopharmacology. *Journal of Child Psychology and Psychiatry and Allied Disciplines* 2001;42(Jan):73–90.

- Riessman CK. Strategic uses of narrative in the presentation of self and illness. *Social Science and Medicine* 1990;30(11):1195–1200. [PubMed: 2360055]
- Ryan ND, Bhatara VS, Perel JM. Mood stabilizers in children and adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry* 1999;38(5):529–536. [PubMed: 10230184]
- Safer DJ, Krager JM. A Survey of Medication Treatment for hyperactive/inattentive students. *Journal of American Medical Association* 1988;260(15):2256–2258.
- Safer DJ, Zito JM, Fine EM. Increased methylphenidate usage for attention deficit disorder in the 1990s. *Pediatrics* 1996;98(6 pt. 1):1084–1088. [PubMed: 8951257]
- Sayer, A. *Realism and Social Science*. London: Sage Publications; 2000.
- Schirm E, Tobi H, Zito JM, de Jong-van den Berg LTW. Psychotropic medication in children: A study from the Netherlands. *Pediatrics* 2001;108(2):30–33.
- Shapiro, T. Developmental considerations in psychopharmacology: The interaction of drugs and development. In: Weiner, JM., editor. *Diagnosis and Psychopharmacology of childhood and adolescent disorders*. New York: John Wiley & Sons, Inc.; 1996. p. 79-95.
- Sleath B. Pharmacist-patient relationships: Authoritarian, participatory, or default? *Patient Education and Counseling* 1996;28:253–263. [PubMed: 8852101]
- Sleath B, Svarstad B, Roter D. Physician vs patient initiation of psychotropic prescribing in primary care settings: A content analysis of audiotapes. *Social Science and Medicine* 1997;44(4):541–548. [PubMed: 9015889]
- Sleator EK, Ullmann RK, von Neumann A. How do hyperactive children feel about taking stimulants and will they tell the doctor? *Clinical Pediatrics* 1982;21(8):474–479. [PubMed: 6123398]
- Stone, Deborah. *The disabled state*. Philadelphia: Temple University Press; 1984.
- Strauss JS. Subjective experiences of schizophrenia: Toward a new dynamic psychiatry–II. *Schizophrenia Bulletin* 1989;15(2):179–187. [PubMed: 2749181]
- Thuppal M, Carlson GA, Sprafkin J, Gadow K. Correspondence between adolescent report, parent report, and teacher report of manic symptoms. *Journal of Child and Adolescent Psychopharmacology* 2002;12(1):27–35. [PubMed: 12014592]
- Tosyali MC, Greenhill LL. Child and adolescent psychopharmacology–Important developmental issues. *Pediatric Clinics of North America* 1998;45(5):1021–1035. [PubMed: 9884673]
- Tyson, P.; Tyson, RL. *Psychoanalytic theories of development: An integration*. New Haven: Yale University Press; 1990.
- Vitiello B. Psychopharmacology for young children: Clinical needs and research opportunities. *Pediatrics* 2001;108(Oct):983–9. [PubMed: 11581454]
- Vitiello B. Pediatric psychopharmacology and the interaction between drugs and the developing brain. *Canadian Journal of Psychiatry-Revue Canadienne De Psychiatrie* 1998;43(6):582–584. [PubMed: 9729684]
- Walkup JT, Cruz K, Kane S, Geller B. The future of pediatric psychopharmacology. *Pediatric Clinics of North America* 1998;45(5):1265–1278. [PubMed: 9884685]
- Werry JS, McClellan JM, Chard L. Childhood and adolescent schizophrenic, bipolar, and schizoaffective disorders: A clinical and outcome study. *Journal American Academy of Child and Adolescent Psychiatry* 1991;30:457–465.
- Wilens, TE. *Straight Talk about Psychiatric Medications for Kids*. New York: Guilford Press; 1999.
- Zito JM, Craig TJ, Wanderling J. Pharmacoepidemiology of 330 child/adolescent psychiatric patients. *Journal of Pharmacoepidemiology* 1994;3(1):47–62.
- Zito JM, Safer DJ. Services and prevention: Pharmacoepidemiology of antidepressant use. *Biological Psychiatry* 2001;49(12):1121–1127. [PubMed: 11430854]
- Zito JM, Safer DJ, dosReis S, Gardner JF, Boles M, Lynch F. Trends in the prescribing of psychotropic medications to preschoolers. *JAMA-Journal of the American Medical Association* 2000;283(8):1025–1030.
- Zito JM, Safer DJ, dosReis S, Gardner JF, Magder L, Soeken K, Boles M, Lynch F, Riddle MA. Psychotropic practice patterns for youth. *Archives of Pediatrics & Adolescent Medicine* 2003;157(1):17–25. [PubMed: 12517190]

Zito JM, Safer DJ, dosReis S, Gardner JF, Soeken K, Boles M, Lynch F. Rising prevalence of antidepressants among US youths. *Pediatrics* 2002;109(5):721–727. [PubMed: 11986427]