

PSYCHOPHARMACOLOGY

A Qualitative Study of Antipsychotic Medication Experiences of Youth

Andrea L. Murphy BScPharm, PharmD^{1,2}; David M. Gardner MSc, PharmD^{1,2};
Steve Kisely MD, PhD³; Charmaine Cooke BScPharm, MSc⁴;
Stan P. Kutcher MD, FRCPC^{2,5}; Jean Hughes RN, PhD⁶

Abstract

Objective: To explore the lived experience of youth who are prescribed antipsychotics. **Methods:** We conducted an interpretive phenomenology study of young people with recent experience of taking antipsychotics. Youth were interviewed and a staged approach was used for data analysis of transcriptions. We collected approximately 13 hours of audio from 18 youth aged 13 to 26 years between January and August of 2010. **Results:** Ambivalence was significant and antipsychotic adverse effects frequently tempered benefits. Both illness and antipsychotics had significant impacts on physical and mental wellbeing with adverse effects on relationships and functioning in various contexts (e.g., school). Stigma related to both antipsychotics and illness was also prominent. Participants' limited knowledge about their antipsychotics and pressure to conform within their youth culture and context affected decisions on starting, adhering to, and persisting with treatment. **Conclusions:** The lived experience of youth taking antipsychotics is complex and the benefits (e.g., symptom improvement) and consequences (e.g., adverse effects) associated with antipsychotics affect all facets of life. More research is needed to better understand youth priorities in treatment decisions and whether youth who demonstrate substantive gaps in their knowledge about antipsychotics are truly given the opportunity to be informed and engage in management decisions including whether to initiate, persist with, and discontinue treatments.

Key Words: antipsychotic agents, qualitative research, pediatrics, young adults, physician-patient relations, decision-making

Résumé

Objectif: Explorer l'expérience vécue d'adolescents à qui on a prescrit des antipsychotiques. **Méthodes:** Nous avons mené une étude interprétative phénoménologique auprès de jeunes gens qui ont récemment fait l'expérience de prendre des antipsychotiques. Les jeunes ont été interviewés et une approche graduelle a servi à l'analyse des données des transcriptions. Nous avons recueilli environ 13 heures d'enregistrement audio auprès de 18 jeunes de 13 à 26 ans, entre janvier et août 2010. **Résultats:** L'ambivalence était significative et les effets indésirables des antipsychotiques en ont souvent modéré les avantages. Tant la maladie que les antipsychotiques avaient des effets significatifs sur le bien-être physique et mental, et des effets indésirables sur les relations et le fonctionnement dans divers contextes (p. ex., l'école).

¹ College of Pharmacy, Dalhousie University, Halifax, Nova Scotia

² Department of Psychiatry, Dalhousie University, Halifax, Nova Scotia

³ School of Population Health, University of Queensland, Herston, Queensland, Australia

⁴ Department of Health and Wellness, Halifax, Nova Scotia

⁵ Sun Life Financial Chair in Adolescent Mental Health, Dalhousie University/IWK Health Centre, Halifax, Nova Scotia

⁶ School of Nursing, Dalhousie University, Halifax, Nova Scotia

Corresponding E-mail: andrea.murphy@dal.ca

Submitted: April 17, 2014; Accepted: August 20, 2014

Les stigmates liés à la maladie et aux antipsychotiques étaient également prédominants. Les connaissances limitées des participants de leurs antipsychotiques et la pression de se conformer à la culture et au contexte des jeunes influaient sur leur décision de commencer le traitement, de l'observer et d'y persister. **Conclusions:** L'expérience vécue de jeunes qui prennent des antipsychotiques est complexe et les avantages (p. ex., l'amélioration des symptômes) et conséquences (p. ex., les effets indésirables) associés aux antipsychotiques affectent toutes les facettes de la vie. Il faut plus de recherche pour mieux comprendre les priorités des jeunes dans les décisions liées au traitement, et pour déterminer si l'on donne réellement aux jeunes qui démontrent des lacunes substantielles dans leurs connaissances des antipsychotiques l'occasion d'être informés et de prendre des décisions quant à la prise en charge, notamment commencer le traitement, persister et abandonner.

Mots clés: agents antipsychotiques, recherche qualitative, pédiatrie, jeunes adultes, relations médecin-patient, prise de décision

Introduction

Antipsychotics are a mainstay of treatment for people with serious mental illness including psychotic disorders (e.g., early psychosis, schizophrenia). Prescription of second generation antipsychotics to people under 25 years of age continues to increase (Alessi-Severini, Bisconti, Collins, Sareen, & Enns, 2012; Cooper et al., 2006; Harrison-Woolrych, Garcia-Quiroga, Ashton, & Herbison, 2007; Murphy et al., 2013; Olfson, Blanco, Liu, Wang, & Correll, 2012; Pringsheim, Lam, & Patten, 2011; Rani, Murray, Byrne, & Wong, 2008; Vitiello et al., 2009; Zito et al., 2008) despite controversy regarding effectiveness and safety data (Canadian Adverse Reaction Newsletter, 2012; Panagiotopoulos, Ronsley, Elbe, Davidson, & Smith, 2010; Pringsheim, Lam, Ching, & Patten, 2011; Seida et al., 2012). Young people's experiences of psychotropics, especially antipsychotics, have not been substantively explored. There is some information on their perceptions of effects on their bodies, behaviours, thoughts, and hopes (Floersch, 2003; Floersch et al., 2009; Longhofer & Floersch, 2010; Moses, 2011) but less on emotions, cognitions, and social functioning. A greater understanding regarding emotions, cognitions, social functioning, and coherence of youth prescribed these medications is of particular importance for clinicians, patient advocates, and policy makers (Friedli, 2009). In this paper, we report our findings from an interpretive phenomenological analysis of young people's experience with antipsychotics.

Methods

Interpretive phenomenological analysis examines the lived experience within a particular situation/context (Benner, 1985; Smith, Flowers, & Larkin, 2009) and includes a "double hermeneutic" (Smith et al., 2009) in which the researcher makes sense of the participant, who, in turn, makes sense of their own experience.

Sample and recruitment procedures

Recruitment was purposeful (Smith et al., 2009) and targeted youth aged 11 to 25 years with a mental illness prescribed at least one antipsychotic within the last two years.

Low-income youth, including those receiving public assistance for income and other expenses (e.g., prescriptions), were originally sought based on our pharmacoepidemiological study, (Murphy et al., 2013) but we eliminated this criterion due to insufficient recruitment. The recruitment process was informed by clinical experience and the literature (Ford et al., 2008; Furimsky, Cheung, Dewa, & Zipursky, 2008; Mapstone, Elbourne, & Roberts, 2007; Morse, Barrett, Mayan, Olson, & Spiers, 2002; Robinson & Trochim, 2007; Woodall, Morgan, Sloan, & Howard, 2010). Interpretive phenomenology studies often use smaller sample sizes (e.g., one to ten) (Smith et al., 2009) owing largely to a commitment to idiography and an aim to gain deep understanding of particular phenomena in particular contexts (Smith et al., 2009). We aimed to recruit 24 participants, which is more than typically needed, in consideration of possible cognitive issues with participants.

Compensation

All participants were paid a one-time honorarium for their participation.

Data collection and analysis

Interviews were conducted by one individual using a semi-structured interview guide (available upon request), which included questions such as, "what is your experience with antipsychotic medications?" The interviewer was equipped with a list of brand and generic names of psychotropics, including antipsychotics available on the Canadian market. The interviewer and the participant used this list to determine which medications they were discussing. All encounters were recorded, transcribed, and analyzed, and anonymized through assignment of false initials. One participant requested not to be recorded. Data collection occurred from January to August 2010 and was stopped following 18 interviews (13 audio hours) of youth aged 13 to 26

Table 1. Interpretive phenomenological analysis process*
(Diekelmann, Allen, & Tanner, 1989; J. A. Smith et al., 2009; J. A. Smith & Osborn, 2008; Van Manen, 1989)

	Activities	Purpose
Stage one	Transcripts were read individually as whole.	To gain a complete picture of the data. To reflect on expressing text meaning with one or more "sententious phrases" (Van Manen, 1989).
Stage two	Summarized the transcripts and identified themes. Text quotes were provided within themes to demonstrate support.	The themes were used to serve as experiential structures of the phenomenon (Van Manen, 1989). Themes and interpretations served as main discussion at meetings as we worked to achieve consensus within themes. To enable the team to examine meaning for participants having their experiences in their specific context (Smith et al., 2009).
Stage three	Continued with independent analysis of transcripts.	To individually compare interpretations of the themes with supporting text.
Stage four	Sought to examine relational themes present in all transcripts.	To enable moving from the particular to the shared (Smith et al., 2009; Streubert & Carpenter, 2011) across multiple experiences. To capture phrases that embodied the main thrust of the meaning of the themes (Van Manen, 1989).
*Conducted by ALM, DMG, and JH		

years because of the richness of the data collected. Two 26 year-olds participated as current antipsychotic experience included their 25th year. Two youths taking antidepressants only were inadvertently interviewed and excluded. We followed a staged iterative and inductive analysis approach (Table 1). Participants were sent findings and themes for review and comment for member-checking. Participants were also contacted, if they consented, for community knowledge translation (KT) sessions regarding the study findings. The KT session was used for feedback, member-checking, and data triangulation (Streubert & Carpenter, 2011). Iterative analyses and participant opportunity for review of findings served as multiple lenses for establishing credibility, dependability, and validity (Creswell & Miller, 2000; Krefting, 1991).

Ethical approvals

Ethics approval was obtained from the research ethics boards (REB) of Capital District Health Authority and the IWK Health Centre. Both of these REBs have reciprocal ethical agreements with Dalhousie University's REB.

Results

The youth experience of antipsychotics was infrequently one of monotherapy, past or current, and many youth had exposure to several classes of psychotropics (Table 2). Similarly, the range of diagnoses as youth understood and described them included many symptoms and terminology from a variety of conditions. We depict the youth antipsychotic experience with the metaphor "double-edged saw" (Figure 1), which represents major components of

experience including significant ambivalence, desires for alternatives, support gaps, and stigma.

Ambivalence

We identified themes related to desires for alternatives, support gaps, and stigma, which all contributed to ambivalence and decisional conflict. This ambivalence and decisional balancing activities of youth significantly affected whether they would start, continue with, or stop antipsychotics. Perceived benefits were often described tentatively and juxtaposed with adverse consequences or as tempering of symptoms (e.g., "level out", "calm", "smoothing out", "balance", "mellow"). Adverse effects impacted mental functioning and sense of self (e.g., "muted", "below par", "grey", "zombie") as often as they were described in causing physical symptoms (e.g., weight gain, high blood sugar, shaking). These effects were often used in examples to describe daily situations that changed with medications such as when interacting with peer groups. Strategies to overcome these effects included altering doses, stopping their medications, or using illicit substances. Stigma was also prominent in the discussions and threaded through other themes including ambivalence.

Elliot described accepting antipsychotics and adverse effects in light of the benefits gained:

"Respondent (R):...it was like the lesser of two evils....You can be scared and paranoid or you can have no saliva. I was going to take the no saliva but...it was trial and error...I'm glad I got to the stage...where I actually feel like they are working."

Table 2. Youth participant demographics and self-reported current and past medications and illness descriptors

Youth	Age	Self-reported illness descriptors transcribed as verbally reported	Self-reported medication(s) current and past, transcribed as verbally reported
1. Tiffany (F)	19	Bipolar, depressed, mood disorder, anxiety, panic attacks	quetiapine, Strattera, Adderall
2. Kelly (F)	26	Psychosis, Psychosis NOS, sleep disorder	olanzapine, lorazepam, risperidone, citalopram, trazodone
3. Billy (M)	25	Psychosis	risperidone, olanzapine, ziprasidone, citalopram
4. Elliot (M)	24	Depression, paranoid, bipolar schizophrenia, bipolar, schizo-affective, schizophrenia with bipolar	Paxil, lithium, "a lot of different antipsychotics"
5. Pheobe (F)	18	OCD, anxiety	quetiapine, Cipralext, clonazepam
6. Sara (F)	21	Schizophrenic, bipolar	quetiapine, lorazepam, Risperidal, Celexa, Effexor
7. Luc (M)	24	Psychosis	risperidone
8. Graham (M)	17	Paranoia	quetiapine
9. Craig (M)	26	ADHD, bipolar schizophrenic	divalproex, olanzapine
10. Chloe (F)	23	Drug-induced psychosis, paranoid schizophrenia, ADHD, anxiety	Cipralext, Wellbutrin, clonazepam, risperidone
11. Jenny (F)	25	Anxiety, depression, bipolar, manic	lithium, olanzapine, citalopram, Cipralext, citalopram, Wellbutrin, zopiclone
12. Meagan (F)	21	Borderline personality disorder	quetiapine, Zoloft, risperidone, Prozac, Paxil, lorazepam, clonazepam, diazepam, lorazepam
13. Beth (F)	22	Bipolar, psychosis	lithium, risperidone, ziprasidone, Cipralext, Epival
14. Gordon (M)	20	ADHD, ADD, seizure disorder, autism	risperidone, Dexedrine, Ritalin, Wellbutrin
15. Steve (M)	13	ADHD, anger problem, violent behaviour	Biphentin, risperidone
16. Brandon (M)	17	Suicidal, dysthymia	Seroquel
17. Kent (M) (Not recorded)	19	Paranoia, hearing voices	olanzapine, risperidone, clozapine, "an antidepressant"
18. Tim (M)	16	Blood pressure, psychotic	risperidone, lorazepam, olanzapine, ziprasidone

M = male, F = female

Luc similarly described accepting antipsychotics following an evolution in his experience:

"R: ...and I went off my pills ...By choice...Because I had an issue with taking them. I don't mind taking them now but I had an issue...Interviewer (I):... What was the issue? R: ...like energy levels, the way it made me feel. It was almost as if taking the pill was causing depression. ...it took me time to adjust knowing that I need to take them, knowing that it's important. ...I feel better now that I've kind of agreed to take my medication."

Graham accepted treatment despite changes and trade-offs with symptom management:

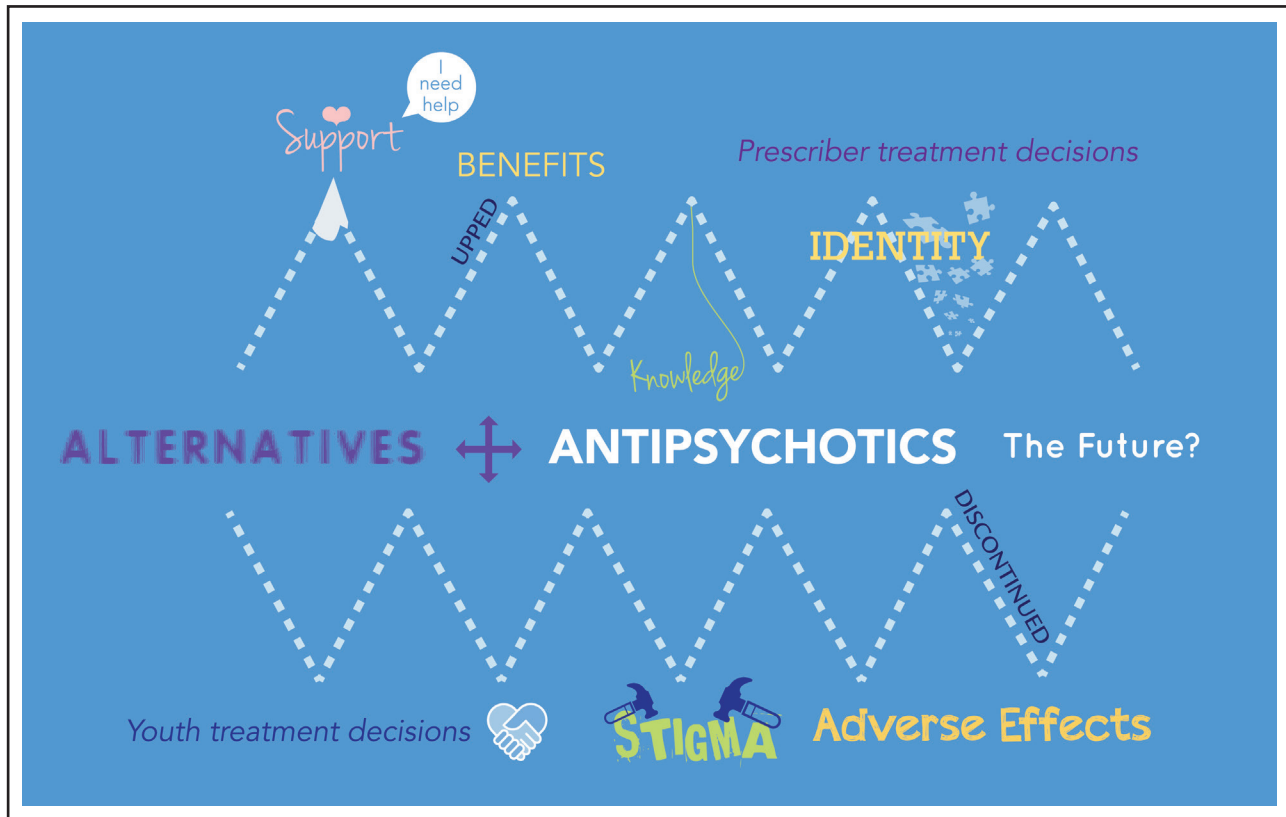
"R: It's good because it definitely muted any kind of weirdness...but it almost like kept you at a below par level. And when I say par... you can never like experience the highs anymore. It was just like grey."

For Chloe, the acceptance of treatment included becoming part of a different peer group:

"R:...I have a different type of friends now... Because after I got sick, I felt like I wasn't the same person. ...I couldn't be myself around other people...I was so empty and I was tired and drugged out and numbed out...I can remember feeling shitty about myself because I felt like a zombie. I didn't feel like myself. I had no concentration."

She also reported using illicit drugs to manage antipsychotic effects:

"R:...I battled with drug usage...when you're on antipsychotics...they don't make you feel like yourself. And even though you may adjust to them, meaning forget how you used to feel, you still crave that feeling of chattiness and just being more like yourself. And that is why I used to use drugs."

Figure 1. Youth antipsychotic experience as a double-edged saw

Youth participants' experiences with antipsychotics, reflecting the ambivalence, tension and vacillating nature of the relationship between youth and their medicine. Youth ambivalence and conflict with treatment co-existed with a desire for alternative therapies represented by the saw teeth and the physical use of the saw (i.e., push and pull). There were significant gaps in knowledge, access to adequate information, and personal and health care service supports experienced by youth in our study and are represented by the saw teeth. These gaps were often acknowledged and seen as significant for youth but they had limited ability and understanding about how to bridge the gaps. Ultimately, this led to placement of the prescriber and youth treatment decisions on opposing sides with a disconnect between the groups. The metaphor serves to depict the language used by youth in the journey of starting and persisting with treatments in a passive manner with changes being done to them as opposed to an active participant in decision-making. They discussed being "upped", "discontinued", "tapered off", as instructed by clinicians and also their own process of tapering or stopping medications in an undulating pattern.

Desires for alternatives

Many questioned the utility of antipsychotics with a desire for overcoming illness without medications through their own strengths (i.e., "beat" the illness "myself"), or using other alternatives such as "holistic", "natural", or "herbal" remedies.

Graham:

"R: ...they definitely are a good thing but I don't really want to use them as a crutch. ...I just want to get over it. Which is good."

Kelly and Sara shared views regarding herbals:

Kelly: "R: ...there's got to be other ways. There's got to be like holistic things...like healthy things I can do to prevent my mind from going nuts....I know they can help like when you really need them. It's

just the doctors are there to recognize like when you really need them....I mean people I meet and are taking medication, I never suggest... "Oh, stop taking them. Those are terrible." ...There has to be more like holistic, I don't know, therapy."

Sara:

"R: ...If I have a problem, I'd rather beat it myself than breaking down and letting something else take care of it. ...I think there's better ways to go about getting through that and stuff. I think they should be really looking at herbal remedies more so than that. There's more healthier ways about it....herbal remedies."

Pheobe justified antipsychotic use based on severity:

"R: I think that they should be used not as a last

resort because I don't think anybody should have to go through hell to get them or have to be really, really, really bad that they risk not being able to get better....they shouldn't be prescribed like candy...or as frequently as SSRIs are because they are a really heavy drug....if there's more gain than risk, and the person is willing to try it, that they should be able to go on them....they should definitely be supervised while they are on it, and be able to ask questions... And...have therapy with it. Because generally when you are on an antipsychotic, it's for something quite severe. Or hopefully it's for something quite severe....They should definitely have follow-up care to help them, not just help the dopamine."

Gaps in support

Support gaps were evident in many areas (e.g., knowledge, peers, family, health services, goal and priority setting) that would be considered necessary to make informed treatment choices and recover from illness. Many participants were unable to contextualize or quantify risks or benefits of treatments. For some, the risks of treatments led to gaps in peer supports and loss of relationships, stigma, and future concern for disclosures.

Chloe described a lack of support from a previous partner and anticipated the future with a "bomb" (i.e., awesome or great) partner:

"R: ...He was like "oh, at least I don't take meds once a month". I was like, "who cares? At least I know they are good for me"....You know, I'm worried that I might meet this bomb guy and that I might have to hide it from him, and then all of a sudden he finds this purse full of pills and he's like, "What the hell?"... "Wow, this girl is a pharmacy on wheels." And it does create...worry that somebody will judge me and think, "oh, she's crazy". Even though I know I'm not."

She also discussed her lack of involvement in decisions about her care while experiencing loss of family supports after hospitalization:

"I: ...and how you were involved in making decisions about your care. R: ...I think it was mostly enforced on me. I was told I had to take this medication.... when I was discharged from the hospital, ...at the last minute, my dad says, "No, you can't stay with me." So like within 3 days before I had to leave the hospital, I had to make a quick decision in the frail state that I was in..."

Jenny described a supportive network with family and friends. She also had praise for her doctors yet she conveys in her story a patchwork of accessibility challenges and concern from her mother regarding accessibility of a care provider:

"R: ...My family doctor, I could see probably at the drop of a hat. I mean she is a very busy woman but I have a few connections. My psychiatrist, she's always said, "If you ever need me, you have to call me." And I have called just about blood work or different things. But she's a very, very busy woman, and she travels I think 18 weeks out of the year for conferences and vacation. So my mom, when I came out of the hospital the second time, was a little scared or was hesitant about going back knowing that that was my only doctor to fall onto. But like Dr. [name] from [hospital] said, "if there's anything ever you need..." I have his information."

She also described serendipitous discovery of adverse effects despite reporting good relationships with her physicians:

"I: And is menstruation stopping a side effect? R: Yes. I: And did they tell you about that? R: No one told me. I looked that up under the side effects. I: What were you told, do you remember? R: For side effects? Nothing. I: Nobody told you any side effects for lithium or olanzapine? R: No, not until I started seeing...my psychiatrist, I would tell her my side effects and she'd say, "Yes." Like she'd nod and say like, "Yes, that is normal." So she's never given me any reason to believe that these side effects are something...I: Extreme. R: Yes."

Youth like Luc used various information sources including physicians, peer groups, the Internet, and the pharmacy "print-off":

"R: I get my information from my psychiatrist, and I got the print-off from...Well, you know when you see prescriptions anyway, the list of side effects that you may or may not get. And it's like umpteen million....with Risperdal...it can cause permanent diabetes. And my blood sugar levels are a little bit high since I've been taking the pill...inability to conceive children. That's also a possibility. And I'm worried about that one...I get this list of side effects, and I'm like, "Ah, what am I going to get?"

Another important gap in knowledge for many youth was long-term treatment expectations.

Beth:

"I: ...what kind of conversations are you having about the long term plan for you [with psychiatrist]? R: I don't think we've had any long-term plans. He's asked me like my education goals...But nothing beyond that...I: Have you been told anything about how long you might be on the antipsychotic? R: Oh, I just figured it was indefinitely...I: What do you know about the side effects?...R: Well, I know it affects my heart because it changes the rhythm. But

I actually don't know all there is to know about it. I just know what's on the medication info, whatever comes with the medication."

Support gaps and stigma were evident in the school system. Steve had negligible involvement in decision-making and the school personnel had influence with treatments:

"R: ...my EA [educational assistant] said I should be put on another kind of medication. Because she used to work as a [health care professional]. ...I: ... your EA was talking to you and was wondering if maybe something else might be better? R: Yes. I: And so what happened then? R: I went to the doctor and got on another kind of pill...I: The risperidone... your EA is talking to you about changing pills.... So when he [the doctor] was suggesting another medicine, did he talk to you about what it might be like to take it? ...What did he tell you?...R: Actually, he mostly talked to my mother. I: ...Were you in the room? R: Yes. I: But you didn't feel like he was talking to you? R: Not really. I: Did you feel like you could ask questions? R: No."

For Gordon, medications were stigmatizing and his experience demonstrated a lack of support from school personnel. Changes in his behaviour were attributed to a lack of medications:

"R: ...they'd be like, "Oh, you're acting weird now. Did you take your medicine this morning?"

Tim also discussed stigma and lack of support from peers and his father while managing potentially severe side effects in front of his friends:

"I: Do they [the school] talk to you about it at all? R: They ask me if I need them sometimes.... The teachers, the kids there are okay...Sometimes they'll say names to me...I'm not supposed to react to it. I:...Do you talk about your medicine with your friends...? R: Well, when my eyes roll up, I have to explain something to them or else they'll just think I'm weird...I said it was from...my other pills. I don't think I should have did that...they kept on asking me why I was looking up, and why I took that orange pill when they weren't looking. I:...you said maybe you shouldn't have [told them]. Why? R: Because they know and they're not supposed to. That is what my dad said."

Discussion

Youth in our study expressed significant ambivalence about antipsychotics, fuelled by a lack of information about both their treatment and illness, and stigma that prevented conformity within their culture and context (e.g., school). Our findings raise questions around informed consent including

when and how frequently these discussions occurred taking into account cognitive abilities, illness severity, and capacity. The process of self-determination (Cook & Jonikas, 2002) and navigating decisional junctures, (i.e., seeking help, accepting treatment, continuing treatment, and deciding to stop medication) (Malpass et al., 2009), in our participants' experiences appeared inadequately supported by clinicians and others (e.g., family, peers, Internet). The traditional or paternalistic decision-making model (Charles, Gafni, & Whelan, 1999) appeared to predominate in the participants' experiences, which supports findings that in psychiatry there is variability in application of decision-making approaches with paternalistic (or traditional) decision-making models reported as a preferred method by prescribers (Hamann et al., 2009; Hamann et al., 2012; Hamann, Leucht, & Kissling, 2003). As a result, youth relied on personal experience and incomplete information from sources that ranged in credibility.

Our findings highlight the importance of national and international initiatives that encourage patient-centered care and involvement in treatment decision-making (Chow, Basky, Teare, & Health Quality Council, 2009; National Health and Medical Research Council, 2004). Unfortunately, to our knowledge shared decision-making models have not been applied to children or young people taking psychotropics, especially antipsychotics (Moses, 2011).

Limitations

We did not specifically request information or have access to medical records to verify diagnoses or specific names of antipsychotics. Participants reported both a wide range of medications including antipsychotics, as well as diagnoses and/or symptoms. This may have affected their ability to accurately identify all the medications they were prescribed and if experiences were specific to antipsychotics. It is also possible that recall and responses may have been affected by illness, side effects from treatments, or the youth's readiness and willingness to engage in treatment discussions. Although the sample size is suitable for an interpretive phenomenological study with rich description, the experiences and our interpretation are only of the youth that were interviewed. We cannot claim that our interpretation of the data is the only possible interpretation.

Recommendations for clinical practice and research:

- Clinicians and patients alike need to know that antipsychotic-related decision-making is to be a fluid, longitudinal process involving clinicians, patients, and (when appropriate) their families and/or support people, recognizing that factors influencing decisions are dynamic and can change over time. Setting and re-visiting treatment goals and evaluating

patient progress and information needs are to be routinized in practice settings through efficient and effective strategies and techniques. Examples include: environmental restructuring with electronic health record-based prompts that can assist prescribers in asking youth about progress and updating goals for treatment; and the use of resources such as Med Ed (Murphy, Gardner, Kutcher, Davidson, & Manion, 2010), that enable youth to actively engage in seeking medication information towards informed decision-making. Implementing these resources in practice may require support (e.g., personnel, technological, or financial) that extends beyond the means of individual clinicians.

- Clinicians should be cognizant that antipsychotic-related decisions will occur at times when youth are experiencing challenges with one or more of various domains of brain functioning including cognition, perception, emotion, behaviour, somatic, and signaling, which may ultimately impact capabilities and motivations to make decisions. Information sharing therefore needs to be included at all patient care visits with modification of the complexity of the information to meet the patient's capacity and level of engagement. When several health care providers or teams are involved, such as during transitions of care (e.g., inpatient to outpatient, pediatric to adult), clear communication processes among providers and patients and/or families need to be in place.
- Research is needed to examine ways to improve shared or informed decision-making for youth of various ages taking antipsychotics. This will require exploration of strategies and techniques for changing behaviours of clinicians, patients, and families (when applicable) in clinical encounters. Although there are a host of potential tools and techniques available (e.g., decision aids, goal setting, action planning, etc.) we have very little information on the mechanisms and techniques for changing behaviour that are the most appropriate and efficient. One technique that shows promise is motivational interviewing (Hamrin & McGuinness, 2013), which is an approach that has been applied to antipsychotics (Kisely, Ligate, Roy, & Lavery, 2012) yet more information is needed to fully appreciate the efficacy and feasibility of these kinds of interventions in daily practice.

Conclusions

The lived experience for youth taking antipsychotics is complex and the benefits and consequences associated with antipsychotics affect all facets of life. Significant ambivalence exists for youth who are prescribed antipsychotics. More research is needed to better understand whether youth are truly informed in their choices to initiate, persist with,

and discontinue antipsychotics given complexities (e.g., stigma, developmental stage, potential for multiple medication usage) and the significant gaps in their knowledge.

Acknowledgements/Conflicts of Interest

The study was funded by Nova Scotia Health Research Foundation (NSHRF). The research team is independent of the funding agency and the funding agency was not involved in the design, interpretation, or writing of the manuscript. Publication of results was specified as component of the dissemination strategy but the decision to publish and content to be published was the decision of the researchers.

References

- Alessi-Severini, S., Biscontri, R. G., Collins, D. M., Sareen, J., & Enns, M. W. (2012). Ten years of antipsychotic prescribing to children: A Canadian population-based study. *Canadian Journal of Psychiatry, 57*(1), 52-58.
- Benner, P. (1985). Quality of life: A phenomenological perspective on explanation, prediction, and understanding in nursing science. *Advances in Nursing Science, 8*(1), 1-14.
- Canadian Adverse Reaction Newsletter. (2012). *Second-generation antipsychotics and cardiometabolic adverse reactions*. (No. 22) Retrieved from: http://www.hc-sc.gc.ca/dhp-mps/medeff/bulletin/carn-bcei_v22n1-eng.php.
- Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician-patient encounter: Revisiting the shared treatment decision-making model. *Social Science & Medicine, 49*(5), 651-661.
- Chow, S., Basky, G., Teare, G. F., & Health Quality Council. (2009). *Shared decision making*. Saskatoon, Sask.: Health Quality Council. Retrieved from http://hqc.sk.ca/Portals/0/documents/Shared_Decision_Making_Report_April_08_2010.pdf
- Cook, J. A., & Jonikas, J. A. (2002). Self-determination among mental health consumers/survivors: Using lessons from the past to guide the future. *Journal of Disability Policy Studies, 13*(2), 88-96. doi: 10.1177/10442073020130020401
- Cooper, W. O., Arbogast, P. G., Ding, H., Hickson, G. B., Fuchs, D. C., & Ray, W. A. (2006). Trends in prescribing of antipsychotic medications for US children. *Ambulatory Pediatrics, 6*(2), 79-83. doi:10.1016/j.ambp.2005.11.002.
- Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into Practice, 39*(3), 124-130. doi:10.1207/s15430421tip3903_2
- Diekelmann, N., Allen, D., & Tanner, C. (Eds.). (1989). *A hermeneutic analysis of the NLN criteria for the appraisal of baccalaureate programs. The NLN criteria for appraisal of baccalaureate programs: A critical hermeneutic analysis (pp 11-34)*. New York, NY: National League for Nursing.
- Floersch, J. (2003). The subjective experience of youth psychotropic treatment. *Social Work in Mental Health, 1*(4), 51-69. doi:10.1300/J200v01n04_04
- Floersch, J., Townsend, L., Longhofer, J., Munson, M., Winbush, V., Kranke, D.,...Findling, R. L. (2009). Adolescent experience of psychotropic treatment. *Transcultural Psychiatry, 46*(1), 157-179. doi:10.1177/1363461509102292
- Ford, J. G., Howerton, M. W., Lai, G. Y., Gary, T. L., Bolen, S., Gibbons, M. C.,...Bass, E. B. (2008). Barriers to recruiting underrepresented populations to cancer clinical trials: A systematic review. *Cancer, 112*(2), 228-242. doi:10.1002/encr.23157
- Friedli, L. for the WHO Regional Office for Europe. (2009). *Mental health, resilience and inequalities*. World Health Organization.
- Furimsky, I., Cheung, A. H., Dewa, C. S., & Zipursky, R. B. (2008). Strategies to enhance patient recruitment and retention in research

- involving patients with a first episode of mental illness. *Contemporary Clinical Trials*, 29(6), 862-866. doi:10.1016/j.cct.2008.07.005
- Hamann, J., Leucht, S., & Kissling, W. (2003). Shared decision making in psychiatry. *Acta Psychiatrica Scandinavica*, 107(6), 403-409.
- Hamann, J., Mendel, R., Buhner, M., Kissling, W., Cohen, R., Knipfer, E., & Eckstein, H. H. (2012). How should patients behave to facilitate shared decision making--the doctors' view. *Health Expectations*, 15(4), 360-366. doi:10.1111/j.1369-7625.2011.00682.x
- Hamann, J., Mendel, R., Cohen, R., Heres, S., Ziegler, M., Buhner, M., & Kissling, W. (2009). Psychiatrists' use of shared decision making in the treatment of schizophrenia: Patient characteristics and decision topics. *Psychiatric Services*, 60(8), 1107-1112.
- Hamrin, V., & McGuinness, T. M. (2013). Motivational interviewing: A tool for increasing psychotropic medication adherence for youth. *Journal of Psychosocial Nursing and Mental Health Services*, 51(6), 15-18.
- Harrison-Woolrych, M., Garcia-Quiroga, J., Ashton, J., & Herbison, P. (2007). Safety and usage of atypical antipsychotic medicines in children: A nationwide prospective cohort study. *Drug Safety*, 30(7), 569-579.
- Kisely, S., Ligate, L., Roy, M. A., & Lavery, T. (2012). Applying motivational interviewing to the initiation of long-acting injectable atypical antipsychotics. *Australasian Psychiatry*, 20(2), 138-142. doi:10.1177/1039856212437257
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy*, 45(3), 214-222.
- Longhofer, J., & Floersch, J. (2010). Desire and disappointment: Adolescent psychotropic treatment and adherence. *Anthropology & Medicine*, 17(2), 159-172. doi:10.1080/13648470.2010.493599
- Malpass, A., Shaw, A., Sharp, D., Walter, F., Feder, G., Ridd, M., & Kessler, D. (2009). "Medication career" or "moral career"? the two sides of managing antidepressants: A meta-ethnography of patients' experience of antidepressants. *Social Science & Medicine*, 68(1), 154-168. doi:10.1016/j.socscimed.2008.09.068
- Mapstone, J., Elbourne, D., & Roberts, I. (2007). Strategies to improve recruitment to research studies. *Cochrane Database of Systematic Reviews (Online)*, (2)(2), MR000013. doi:10.1002/14651858.MR000013.pub3
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1(2), article 2. Retrieved from http://www.ualberta.ca/~iiqm/backissues/1_2Final/pdf/morseetal.pdf
- Moses, T. (2011). Adolescents' commitment to continuing psychotropic medication: A preliminary investigation of considerations, contradictions, and correlates. *Child Psychiatry and Human Development*, 42(1), 93-117. doi:10.1007/s10578-010-0209-y
- Murphy, A. L., Gardner, D. M., Cooke, C., Kisely, S., Hughes, J., & Kutcher, S. P. (2013). Prescribing trends of antipsychotics in youth receiving income assistance: Results from a retrospective population database study. *BMC Psychiatry*, 13(1), 198. doi:10.1186/1471-244X-13-198
- Murphy, A., Gardner, D., Kutcher, S., Davidson, S., & Manion, I. (2010). Collaborating with youth to inform and develop tools for psychotropic decision making. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 19(4), 256-263.
- National Health and Medical Research Council. (2004). *General guidelines for medical practitioners on providing information to patients*. Australia: Commonwealth of Australia. Retrieved from http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e57.pdf
- Olfson, M., Blanco, C., Liu, S. M., Wang, S., & Correll, C. U. (2012). National trends in the office-based treatment of children, adolescents, and adults with antipsychotics. *Archives of General Psychiatry*, 69(12), 1247-56. doi:10.1001/archgenpsychiatry.2012.647
- Panagiotopoulos, C., Ronsley, R., Elbe, D., Davidson, J., & Smith, D. H. (2010). First do no harm: Promoting an evidence-based approach to atypical antipsychotic use in children and adolescents. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 19(2), 124-137.
- Pringsheim, T., Lam, D., Ching, H., & Patten, S. (2011). Metabolic and neurological complications of second-generation antipsychotic use in children: A systematic review and meta-analysis of randomized controlled trials. *Drug Safety*, 34(8), 651-668. doi:10.2165/11592020-000000000-00000
- Pringsheim, T., Lam, D., & Patten, S. B. (2011). The pharmacoepidemiology of antipsychotic medications for Canadian children and adolescents: 2005-2009. *Journal of Child and Adolescent Psychopharmacology*, 21(6), 537-543. doi:10.1089/cap.2010.0145
- Rani, F., Murray, M. L., Byrne, P. J., & Wong, I. C. (2008). Epidemiologic features of antipsychotic prescribing to children and adolescents in primary care in the United Kingdom. *Pediatrics*, 121(5), 1002-1009. doi:10.1542/peds.2007-2008
- Robinson, J. M., & Trochim, W. M. (2007). An examination of community members', researchers' and health professionals' perceptions of barriers to minority participation in medical research: An application of concept mapping. *Ethnicity & Health*, 12(5), 521-539. doi:10.1080/13557850701616987
- Seida, J. C., Schouten, J. R., Boylan, K., Newton, A. S., Mousavi, S. S., Beath, A.,...Carrey, N. (2012). Antipsychotics for children and young adults: A comparative effectiveness review. *Pediatrics*, 129(3), e771-784. doi:10.1542/peds.2011-2158
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London, UK: Sage.
- Smith, J. A., & Osborn, M. (2008). Interpretive phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 53-80). London; Thousand Oaks, CA: SAGE Publications.
- Streubert, H. J., & Carpenter, D. R. (2011). *Qualitative research in nursing: Advancing the humanistic imperative* (5th ed.). Philadelphia, PA: Wolters Kluwer Health/Lippincott Williams & Wilkins.
- Van Manen, M. (1989). *Researching lived experience: Human science for an action sensitive pedagogy*. London, ON: Althouse Press.
- Vitiello, B., Correll, C., van Zwieten-Boot, B., Zuddas, A., Parellada, M., & Arango, C. (2009). Antipsychotics in children and adolescents: Increasing use, evidence for efficacy and safety concerns. *European Neuropsychopharmacology*, 19(9), 629-635. doi:10.1016/j.euroneuro.2009.04.008
- Woodall, A., Morgan, C., Sloan, C., & Howard, L. (2010). Barriers to participation in mental health research: Are there specific gender, ethnicity and age related barriers? *BMC Psychiatry*, 10, 103. doi:10.1186/1471-244X-10-103
- Zito, J. M., Safer, D. J., de Jong-van den Berg, L. T., Janhsen, K., Fegert, J. M., Gardner, J. F.,...Valluri, S. C. (2008). A three-country comparison of psychotropic medication prevalence in youth. *Child and Adolescent Psychiatry and Mental Health*, 2(1), 26. doi:10.1186/1753-2000-2-26