

Health Information Preference among Youth and Caregivers related to Second-Generation Antipsychotic Treatment

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Abstract

Objective: To determine the health information-seeking preferences of youth with mental health challenges and their caregivers, focusing on health literacy needs related to second-generation antipsychotics (SGAs). **Methods:** One hundred fifty two youth and 158 caregivers attending outpatient psychiatry clinics at BC Children's Hospital between February 2009 and December 2010 completed a SGA health literacy survey. **Results:** Youth and caregivers placed emphasis on understanding the benefits and side effects of SGA-treatment, along with strategies to prevent potential side effects. While psychiatrists were viewed as a crucial source of information by both groups, pharmacists were an under-utilized resource by youth. Both youth and caregivers preferred brochures from healthcare providers, websites, and support groups to access health information; however, preferences diverged among other activities. Specifically, youth favoured practical, "hands-on" programs such as cooking and exercise classes, whereas caregivers showed greater interest in didactic presentations and conferences. Sex differences were observed in receptiveness towards certain programs and resources. **Conclusions:** The findings from this study support the inclusion of caregivers and youth of both sexes with mental health conditions in the future development of educational resources related to medications such as SGAs. Health literacy strategies need to be multi-faceted, and utilize mixed methods to ensure broad reach and applicability.

Key words: *second-generation antipsychotics, health literacy, patient education, side effects, children, adolescents*

Résumé

Objectif: Déterminer les préférences dans la recherche d'information sur la santé des adolescents souffrant de problèmes de santé mentale et de leurs soignants, en mettant l'accent sur les besoins de littératie en santé relative aux antipsychotiques de deuxième génération (ADG). **Méthodes:** Cent cinquante-deux adolescents et 158 soignants fréquentant des cliniques psychiatriques ambulatoires du BC Children's Hospital entre février 2009 et décembre 2010 ont répondu à un sondage de littératie en santé sur les ADG. **Résultats:** Les adolescents et les soignants ont mis l'accent sur la compréhension des avantages et des effets secondaires du traitement par ADG, ainsi que des stratégies de prévention d'éventuels effets secondaires. Alors que les deux groupes voyaient les psychiatres comme étant une source d'information essentielle, les pharmaciens étaient une ressource sous-utilisée par les adolescents. Les adolescents et les soignants préféraient les brochures des prestataires de soins de santé, des sites Web, et des groupes d'entraide pour avoir accès à l'information sur la santé; toutefois, les préférences divergeaient pour d'autres activités. Spécifiquement, les adolescents aimaient les programmes pratiques comme les cours de cuisine et d'exercice, alors que les soignants ont manifesté un plus grand intérêt pour les exposés didactiques et les conférences. Des différences selon le sexe ont été observées dans la réceptivité à certains programmes et ressources. **Conclusions:** Les résultats de cette étude appuient l'inclusion

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de soignants et d'adolescents des deux sexes souffrant de problèmes de santé mentale dans le futur développement de ressources éducatives liées aux médicaments comme les ADG. Les stratégies de littératie en santé doivent comporter de multiples aspects, et utiliser des méthodes mixtes pour obtenir une vaste portée et applicabilité.

Mots clés: *antipsychotiques de la deuxième génération, littératie en santé, éducation des patients, effets secondaires, enfants, adolescents*

Introduction

Since their introduction in the late 1980s, second generation antipsychotics (SGAs) have become increasingly prescribed among clinicians, due to their lower rates of extrapyramidal symptoms including tardive dyskinesia (Correll, Leucht, & Kane, 2004; Leucht, Pitschel-Walz, Abraham, & Kissling, 1999), their superiority in treating the negative symptoms of psychosis as well as their ability to produce improved cognition in psychosis (Davis, Chen, & Glick, 2003; Kane, Honigfeld, Singer, & Meltzer, 1988; Kumra et al., 1996; Voruganti et al., 2000). However, there is mounting evidence in the adult population linking SGA use to weight gain (Gentile, 2006) and associated metabolic dysregulation, including dyslipidemia (Meyer & Koro, 2004), insulin resistance (Wu et al., 2006), metabolic syndrome (Meyer, Koro, & L'Italien, 2005) and type 2 diabetes (Llorente & Urrutia, 2006; Newcomer, 2005). Furthermore, there is growing literature pointing to similar metabolic side effects in the pediatric population (Correll et al., 2009; Panagiotopoulos, Ronsley, & Davidson, 2009; Panagiotopoulos, Ronsley, Kuzeljevic, & Davidson, 2012).

In spite of these risks, significant gaps exist in health literacy among parents and caregivers of pediatric patients (Fredrickson et al., 1995; Sanders, Federico, Klass, Abrams, & Dreyer, 2009; Sanders, Shaw, Guez, Baur, & Rudd, 2009; Yin et al., 2009), including literacy in mental health (Lazaratou, Anagnostopoulos, Alevizos, Haviara, & Ploumpidis, 2007; Lloyd & Carson, 2005; Sonuga-Barke & Balding, 1993). Furthermore, limitations in mental health literacy of adolescents are increasingly being recognized (Burns & Rapee, 2006; Kelly, Jorm, & Rodgers, 2006; Kelly, Jorm, & Wright, 2007; Rose, Thornicroft, Pinfold, & Kassam, 2007), and the development of child health literacy has been identified as an important goal in improving health disparities and outcomes (Marx, Hudson, Deal, Pateman, & Middleton, 2007; Sanders et al., 2009). Determining the best resources and platforms to disseminate information related to psychotropic medications and healthy living strategies is required in order to promote awareness, build engagement and foster family-centred care among youth living with mental health challenges treated with SGAs and their family members.

Through community-based focus group research engaging caregivers of youth with mental health conditions, we have previously demonstrated the need for consistent, credible

information on SGA-treatment, as well as preventive strategies for side effects, including the promotion of a healthy lifestyle (Chovil & Panagiotopoulos, 2010). Expanding on our past findings, we sought in this study to survey the health information-seeking attitudes of youth with mental health conditions and their caregivers followed at our tertiary care facility, with a focus on youth who have received treatment with an SGA. The goal of our study was to determine whether youth and caregivers have divergent preferences on health education programs, and whether there are determinants that play a role on receptiveness towards these programs within each group. Our study results will be used in the development of resources and delivery platforms that address the specific needs of youth with mental health challenges and their families.

Methods

The study was reviewed and approved by the Children's and Women's Research Review Committee and the University of British Columbia Research Ethics Board.

The study was conducted at child and adolescent outpatient psychiatry clinics of the British Columbia Children's Hospital (BCCH). Youth 12-18 years of age who attended the BCCH outpatient psychiatry clinics between February 2009 and December 2010 were invited to complete the youth survey. Written informed consent was obtained from parents or legal guardians of all participating youth. Caregivers (including parents, guardians and other caregivers) who accompanied youth to their appointments between February 2009 and September 2010, regardless of the youth's age, were also invited to complete the caregiver survey and provided written informed consent.

Surveys

The youth survey consisted of 59 items with multiple choice questions, Likert scales and free responses. To establish the prevalence of SGA prescription and their target indications, respondents were asked to select their mental health condition and their status of SGA treatment. Those who had not taken an SGA were directed to advance to the latter part of the survey. Respondents who self-reported SGA-treatment were asked to proceed to questions on side effects, medication attitudes and their current sources of medication information. Using a Likert scale, questions were posed about these youth's attitudes towards importance of knowledge towards medication benefits, side effects, strategies to

Table 1. Perceived importance of medication knowledge by youth and caregiver respondents

“It is important for me to know...”	Strongly agree %	Somewhat agree %	Not sure %	Somewhat disagree %	Strongly disagree %	Rank sum	Expected	z	p
Benefits of taking medication									
Youth	73.9	13	2.2	4.3	6.5	3984	4554	-2.86	<0.01
Caregivers	90.7	4.0	0.7	0.0	4.6	15519	14949		
Possible side effects									
Youth	71.7	15.2	4.3	2.2	6.5	3849	4554	-3.67	<0.001
Caregivers	92.7	2.6	0.0	0.0	4.6	15655	14949		
How to prevent side effects									
Youth	56.5	26.1	4.3	8.7	4.3	3548	4554	-4.20	<0.001
Caregivers	86.1	7.9	1.3	0.0	4.6	15955	14949		
Alternative options after occurrence of side effects									
Youth	60.9	19.6	6.5	6.5	6.5	3579	4531	-4.24	<0.001
Caregivers	88.7	6.7	0.0	0.0	4.7	15727	14775		

prevent potential side effects and options available in case side effects occurred. They were then asked to identify their sources of medication information from various members they encounter in medical, academic and family settings.

The caregiver survey contained 50 items with a similar format to the youth survey. However, all caregiver respondents were invited to complete questions on medication attitudes and sources of information on medications.

To determine information-seeking preferences, all respondents regardless of SGA-treatment status were invited to rate their preferences for activities and resources aimed at health education using Likert scales. The youth and caregivers each completed a single survey, and the survey questions for youth and caregivers were specifically tailored to each group. Of note, the youth and caregiver responses were not paired as the surveys were independently distributed.

Exclusions

As the survey was specifically designed for youth with mental health conditions and their caregivers, respondents who did not provide answers on questions related to mental health conditions and SGA-treatment status were excluded from the final analysis.

Data Analysis

SPSS (PC Version 19.0, PASW Inc, USA) and STATA version 11.1 (StataCorp LP, USA) were used for data analysis. Percentages and frequencies were used for descriptive data, and responses to Likert scale items were treated as ordinal data. The Wilcoxon rank-sum test was used to compare the responses between youth and caregivers. The test was also used to compare the health information-seeking preferences

within these two groups across sex (male and female), age (12-14, 15-16 and 17-18 years of age) and SGA-treatment status (SGA-naïve, previously SGA-treated, currently SGA-treated). In a rank-sum test, the distribution of Likert scale responses of the two groups was assessed by comparing the actual rank sums against the expected values under the null hypothesis. Those who have a higher actual rank sum in comparison with the expected value are considered as having higher agreement on the Likert scale. As the caregiver survey did not contain questions related to age, this factor was not considered in the caregiver survey analysis. To capture all responses and minimize systematic bias, available case analysis was used for any missing data (El-Masri & Fox-Wasylyshyn, 2005). A *p*-value < 0.05 was considered statistically significant.

Results

Demographics

The consent rate for youth and caregiver surveys was 65% and 89%, respectively. In total, 152 youth and 158 caregiver surveys were analyzed. Among the 152 youth respondents, 51% were male and 77.2% were Caucasian (15.5% Asian/South Asian; 4.4% First Nations; 2.9% Hispanic/Black/Other). Twenty-eight percent were between 12 and 14 years of age, while 41% and 22% fell within the 15-16 and 17-18 years of age categories, respectively. Most frequently reported Diagnostic and Statistical Manual of Mental Disorders, fourth edition, text revision (DSM-IV-TR) Axis I disorders among these youth were anxiety disorders, mood disorders and disruptive behaviour disorders (attention deficient hyperactivity, oppositional defiant and conduct disorders). Three percent of respondents cited psychosis as

Table 2. Sources of medication information by youth and caregiver respondents

"I get my information about medication from..."	Always %	Frequently %	Occasionally %	Rarely %	Never %	Rank sum	Expected	z	p
Family doctor									
Youth	14.0	25.6	30.2	2.3	27.9	3380	3849	-1.63	0.10
Caregivers	28.9	20.0	20.7	19.3	11.1	12552	12083		
Pharmacist									
Youth	9.5	11.9	11.9	28.6	38.1	2102	3675	-5.68	<0.001
Caregivers	33.3	26.5	25.8	8.3	6.1	13124	11550		
Paediatrician									
Youth	23.7	10.5	13.2	2.6	50.0	2479	2774	-1.38	0.17
Caregivers	28.0	15.9	16.8	5.6	33.6	8106	7811		
Psychiatrist									
Youth	47.8	30.4	4.3	4.3	13	3876	3864	0.05	0.96
Caregivers	48.8	23.1	14.9	4.1	9.1	10152	10164		
Therapist/counsellor									
Youth	12.2	7.3	26.8	17.1	36.6	2923	2911	0.06	0.96
Caregivers	15.0	12.0	20.0	9.0	44.0	7088	7100		
School teacher									
Youth	2.4	0.0	4.9	2.4	90.2	2720	2932	-1.46	0.14
Caregivers	4.0	2.0	10.9	3.0	80.2	7433	7221		

one of their mental health conditions, and 15% were unsure of their condition. Thirty-two percent (49/152) were currently or previously treated with an SGA at the time of survey, compared to 44% (67/152) who were naïve to these medications. Twenty four percent (36/152) of respondents were unable to determine if they had received SGA treatment. Within respondents who were certain of their SGA-treatment status and mental health condition (N=116), the disorders most frequently associated with current or past SGA treatment were psychotic, neurodevelopmental (autism, Asperger syndrome, intellectual delay, Tourette syndrome) and mood disorders. Of note, more than 40% of youth across all diagnoses reported treatment with an SGA at one point.

Among the 158 caregiver respondents, 88% were female, and 83% were Caucasian (12% Asian/South Asian; 2% First Nations; 3% Hispanic/Black/Other). Similar distributions of mental health conditions and SGA-treatment status were observed, where 42% (66/158) of respondents' children were SGA-treated compared to 55% (87/158) SGA-naïve. Uncertainty about their children's SGA-treatment status was reported in 3% (5/158) of caregivers.

Perception of the Importance of Awareness of Medication Benefits and Side effects

Over 70% of SGA-treated youth strongly agreed with the importance of understanding potential benefits and side effects of their medications, and over 55% strongly agreed with the importance of knowing prevention strategies and

intervention options should these side effects occur. Comparison of youth and caregiver responses demonstrates statistically significant differences in the importance placed on these factors, whereby stronger sentiments were consistently expressed by caregivers (Table 1). Furthermore, over 60% of caregivers strongly believed that knowledge of side effects would influence their decision to initiate recommended medications for their children. While 20% of caregivers felt weight gain would be a major factor in their decision to stop a child's SGA-treatment, 55%, 53% and 49% held the same view for high blood pressure, abnormal blood glucose and abnormal cholesterol levels, respectively.

Source of Medication Information

Psychiatrists were overwhelmingly chosen by both groups of respondents as an important resource, with 78% of SGA-treated youth and 72% of caregivers frequently or always obtaining information on medications from their psychiatrists. This was followed by family physicians (40%) and pediatricians (34%) in youth respondents. In the caregiver group, the next commonly chosen professionals were pharmacists (60%) and family physicians (49%). Notably, pharmacists emerged as a significant source of medication information for caregivers compared to youth ($z = -5.68$, $p < 0.001$, Table 2).

Role of Family Members

Within the family setting, youth most often (67%) strongly agreed that their mothers held responsibility for education and monitoring of medications, followed by youth

Table 3. Role of family members in providing medication information and monitoring by youth respondents

“In your family, who is the most responsible for learning about and monitoring the medication(s) you are taking?”	Strongly agree %	Somewhat agree %	Not sure %	Somewhat disagree %	Strongly disagree %
My mother	67.4	14.0	4.7	7.0	7.0
My father	42.5	32.5	7.5	10.0	7.5
Both of my parents	40.5	24.3	2.7	10.8	21.6
Me	52.5	35.0	7.5	0.0	5.0
My grandmother	8.6	5.7	0.0	8.6	77.1
My grandfather	2.9	5.7	0.0	8.6	82.9
My other family member	5.7	0.0	2.9	8.6	82.9

themselves (52.5%), fathers (42.5%) and both parents (40.5%, Table 3). For all caregivers surveyed, 59% reported the child’s mother as the individual responsible for medication information and monitoring, while 33.5% reported this as a shared task between both parents. In contrast to youth survey results, only 5% of caregivers reported the child as being responsible for learning about and monitoring their medications.

Educational Programs and Resources

Among educational programs on health and medications, youth respondents favoured formats that included exercise classes (17% strongly agree), cooking classes (15%) and support groups (14%), whereas internet chat lines (6%) and presentations (5%) ranked lowest in this category. In contrast, caregiver respondents were most receptive to presentations (49%), conferences (44%) and support groups (44%). Caregivers also preferred books as a resource, though this preference was not shared by youth respondents. However, some similarities between youth and caregivers were observed. Within informational resources, brochures from health professionals and websites were most preferably ranked by both youth and caregivers, while TV/Radio and social networking sites received low enthusiasm.

Subgroup Analysis of Educational Preferences

Our data indicate that female youth respondents have significantly higher interest toward participation in 6 out of 7 educational activities (Table 4). No statistically significant differences were seen across age or SGA-treatment status (data not shown). Similarly, while neither age nor SGA-treatment was found to be a determinant for resource access among caregivers, female caregivers reported significantly higher enthusiasm for presentation attendance, as well as use of websites and books compared to their male counterparts (Table 4).

Discussion

To our knowledge, this is the first Canadian initiative to assess the health information seeking preferences of youth followed through a tertiary outpatient pediatric mental health facility. Most notably, we confirmed that both youth and caregivers consider it a priority to obtain information related to the benefits and side effects of SGA-treatment, as well as pre-emptive strategies to prevent potential adverse effects of these medications. Our results emphasize the pivotal role played by health care providers, particularly psychiatrists, in patient and family education, strengthening our qualitative focus-group findings (Chovil & Panagioto-poulos, 2010). Pharmacists appear to be under-recognized and under-utilized health information resource among youth; thus, strategies that enhance understanding of their role may have a beneficial impact on health literacy in this population. Within the family setting, it is interesting to note that while 52.5% of youth responded being strongly involved in obtaining information related to their medications, only 5% of caregivers described the same for their children’s involvement. This discrepancy, as well as the intended and actual levels of involvement by youth with mental health conditions undergoing SGA treatment should be the focus of further research.

Presented with a wide range of health education approaches, youth favoured practical, “hands-on” programs such as cooking and exercise classes, whereas caregivers showed greater interest in didactic-based presentations and conferences. However, some overlap did exist between youth and caregiver preferences, with both groups demonstrating interest in support groups, brochures from health professionals, as well as internet websites. Comparable results were observed in a British survey (Powell & Clarke, 2006), where 24% of respondents seeking mental health support rated leaflets and the Internet equally as sources of information they would most likely consult, ranking them highest following consultation with health professionals. In the same survey, newspaper/magazine articles and TV/Radio programs were ranked lowest. In a study specifically addressing information preferences of parents with children having mental health concerns, it was found that pamphlets,

Table 4. Comparison of health information source preference by youth and caregivers stratified by sex

	Strongly agree %					
	Youth			Caregivers		
	Males	Females	Comparison* <i>p</i>	Males	Females	Comparison* <i>p</i>
Programs/activities						
Exercise classes	11.9	22.6	<0.01†	8.7	18.3	0.24
Cooking classes	14.9	14.8	0.29	8.3	11.6	0.09
Support group	6.0	21.0	<0.01†	32.0	45.2	0.08
Summer camp	4.5	14.3	0.04†	-	-	-
Health fair	1.5	14.8	<0.01†	7.7	23.3	0.07
Internet chat line	1.5	11.5	<0.01†	8.3	9.2	0.67
Presentations	3.0	8.2	<0.01†	22.2	54.0	0.03†
Conference	-	-	-	24.0	48.4	0.06
Resources						
Brochure from health professional	24.2	29.2	0.13	59.3	64.6*	0.52
Website	23.1	17.5	0.65	29.6	56.2	0.04†
Newsletter	6.3	5.1	0.99	12.0	30.5*	0.07
Phone line support	3.2	6.3	0.45	20.0	26.1*	0.39
Books	3.2	4.8	0.61	15.4	40.0	0.01†
Social networking	0.0	8.2	0.24	8.0	11.0*	0.36
Newspaper/magazine	3.1	4.8	0.24	11.5	13.9*	0.81
TV/radio	3.1	1.6	0.79	8.0	7.8*	0.59

Conferences and summer camp were not included as part of the youth and caregiver surveys respectively.

*Comparisons were done over entire Likert scale via Wilcoxon rank-sum test.

†*P*<0.05 for comparisons across sex over entire Likert scale.

books and the Internet ranked higher than video/DVD and audio tape/CD (Cunningham et al., 2008).

Within our survey respondents, we noted a higher likelihood among females to attend educational activities on health, a disparity that is not replicated across other factors, such as age or SGA-treatment status. This difference in information- and help-seeking attitudes has been previously identified, with implications for educational resource development (Gasquet, Ledoux, Chavance, & Choquet, 1999; Gould, Munfakh, Lubell, Kleinman, & Parker, 2002; Jorm, Wright, & Morgan, 2007; Reavley, Cvetkovski, & Jorm, 2010). Interestingly, the Internet has been proposed as a medium that can reach out to young males and bridge the divide in health information-seeking between the sexes (Reavley et al., 2010). Expanding on this observation, no significant sex difference was observed in youth willingness to access information-based educational approaches in our study, despite less interest displayed by young males in attending activity-based approaches. Similar results were seen in a recent survey of young Australians with regard to their perception towards helpfulness of websites and books (Oh, Jorm, & Wright, 2009), as well as in a study of New York high school students on the role of the Internet as a

source of help-seeking (Gould et al., 2002). Given higher rates of SGA-treatment among young males than females (Curtis et al., 2005; Olfson, Blanco, Liu, Moreno, & Laje, 2006; Panagiotopoulos, Ronsley, Elbe, Davidson, & Smith, 2010), health literacy strategies that can attract and hold the interest of male participants have the maximal potential to increase awareness and knowledge of medication management and healthy lifestyle.

Building on previous literature (Gould et al., 2002), we found neither youth nor caregivers preferred a single educational program or resource; rather, there were 2 to 3 items in both groups that appear to be equally high-ranking. Taken together, the use of multiple platforms for delivery of health and medication information, such as cooking classes and websites for youth, conferences and support groups for caregivers, and brochures from health professionals for both groups, has the greatest potential to achieve widespread acceptance and reception in the implementation of health literacy initiatives. This is especially important as close to 1 in 4 youth respondents in our survey were unable to determine whether they have received SGA-treatment, despite the question having stated the names of commonly

prescribed SGAs in generic and proprietary names, clearly indicating the need to improve health literacy in this group.

Limitations

The voluntary nature of this study does not allow for evaluation of systematic differences in attitudes and preferences among those who declined to participate. Questions related to SGA-treatment status are also subject to recall error, especially for youth with short trials of SGA treatment that occurred long ago. Finally, the great proportion of Caucasians who responded to the survey may indicate the need for alternative language surveys, or other means of evaluating attitudes of health information seeking in other ethnic groups.

Conclusion

There is a demand by SGA-treated youth and caregivers alike to receive education on potential medication benefits and side effects, as well as pre-emptive strategies to mitigate adverse events. The findings from this study support the inclusion of caregivers and youth of both sexes with mental health conditions in the future development of educational resources related to medications such as SGAs. Health literacy strategies need to be multi-faceted, and utilize mixed methods to ensure broad reach and applicability.

Acknowledgements/Conflicts of Interest

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