

RESEARCH ARTICLE

Exploring the Decisional needs of Parents with Children with ADHD and Disruptive and Aggressive Behaviour

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Abstract

Objective: The aim of this qualitative study was to explore the decisional needs of parents of children with ADHD and disruptive and aggressive behaviour to inform the creation of a patient decision aid. **Method:** A one-day meeting of researchers, community advocacy partners, and 11 parents of children (age range eight to 21) with aggressive and disruptive behaviour associated with a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD), Oppositional Defiant Disorder or Conduct Disorder was held. This meeting consisted of a two-hour educational session on the assessment and management of aggressive and disruptive behaviour in children and patient decision aids, followed by two concurrent focus groups to determine the decisional needs of parents. NVivo11 software was used for the organization of the data. **Results:** The results outline the broad themes and subthemes that emerged from the thematic analysis. These themes and subthemes include (a) decisional needs — treatment options and where to begin, availability, effectiveness of different treatment options, side effects, time, depth of information provided; (b) decision aid formats, and (c) accessibility — language, involvement of children, and dissemination. **Conclusion:** The themes generated from the focus groups suggest that a patient decision aid for parents with children with ADHD and disruptive and aggressive behaviour should follow the general recommendations for best practices for the creation of patient decision aids. Specific information on the regional availability of non-medical treatments will be especially helpful for parents to navigate services and service providers. Consideration should be given as to how the concept of values clarification is introduced to families.

Key Words: ADHD, disruptive and aggressive behaviour, shared decision making, patient decision aid

Résumé

Objectif: Cette étude qualitative visait à explorer les besoins décisionnels de parents d'enfants souffrant du trouble de déficit de l'attention avec hyperactivité (TDAH) et présentant un comportement perturbateur et agressif, dans le but de renseigner la création d'un outil de prise de décision pour les patients. **Méthode:** Une réunion d'un jour de chercheurs, de partenaires de défense communautaire et de 11 parents d'enfants (de 8 à 21 ans) présentant un comportement agressif et perturbateur associé à un diagnostic de TDAH, de trouble oppositionnel avec provocation ou de trouble des conduites a eu lieu. Cette réunion consistait en une séance éducative de 2 heures sur l'évaluation et la gestion du comportement agressif et perturbateur des enfants et sur les outils de prise de décision des patients, suivie de 2 groupes de discussion simultanés pour déterminer les besoins décisionnels des parents. L'organisation des données s'est faite à l'aide du logiciel NVivo11.

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Résultats: Les résultats font ressortir les grands thèmes et sous-thèmes qui sont issus de l'analyse thématique. Ces thèmes et sous-thèmes sont notamment (a) les besoins décisionnels — les options de traitement et par où commencer, la disponibilité, l'efficacité des différentes options de traitement, les effets secondaires, le temps, l'exhaustivité de l'information fournie; (b) les formats des outils de prise de décision, et (c) l'accessibilité — la langue, la participation des enfants, et la diffusion. **Conclusion:** Les thèmes issus des groupes de discussion suggèrent qu'un outil de prise de décision des patients destiné aux parents d'enfants qui souffrent de TDAH et présentent un comportement agressif et perturbateur devrait suivre les recommandations générales des pratiques exemplaires pour la création d'un outil de prise de décision des patients. L'information spécifique sur la disponibilité régionale des traitements non médicaux sera particulièrement utile pour les parents qui cherchent des services et des fournisseurs de service. Il serait bon d'examiner comment le concept de la clarification des valeurs est présenté aux familles.

Mots clés: TDAH, comportement perturbateur et agressif, prise de décision partagée, outil de prise de décision des patients

Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is the most common mental health disorder in school age children, with a community prevalence globally of approximately 5% (Sayal, Prasad, Daley, Ford, & Coghill, 2017). In addition to the core symptoms of inattention and hyperactivity, many children with ADHD suffer from oppositional behaviour, conduct problems, and aggression to varying degrees. Up to 60% of children with ADHD will meet diagnostic criteria for Disruptive Behaviour Disorders including Oppositional Defiant Disorder (ODD) and Conduct Disorder (CD) (Maughan, Stafford, Shah, & Kuh, 2014). Disruptive and aggressive behaviour in the setting of ADHD, ODD and CD is associated with negative long-term psychosocial and health outcomes. Aggression in children is a major risk factor for the development of criminality in adolescence and adulthood (Pingault et al., 2013), and negatively influences quality of life for children and their families (Klassen, Miller, & Fine, 2004; Kuhne, Schachar, & Tannock, 1997). Individuals with ADHD and CD are at higher risk of depression, substance use disorder, poor academic achievement, and unemployment (Erskine et al., 2016). Effective and timely treatment for these children is extremely important to prevent these short- and long-term morbidities.

Canadian guidelines on the treatment of disruptive and aggressive behaviour in children and youth with ADHD, ODD and CD were published in 2015 (Gorman et al., 2015). These guidelines recommend the use of psychosocial and behavioural therapies as the initial treatment, and if these are inadequate, the use of standard ADHD medications as first line pharmacotherapy (if an ADHD diagnosis is present). The guidelines were developed in response to concerning trends observed in the use of antipsychotic medications for children with disruptive and aggressive behaviour (Alessi-Severini, Biscontri, Collins, Sareen, & Enns, 2012; Murphy et al., 2013; Pringsheim, Lam, Ching, & Patten, 2011; Ronsley et al., 2013). A major concern regarding the use of antipsychotics is their propensity to cause metabolic,

hormonal, and extrapyramidal side effects (Pringsheim, Lam, & Patten, 2011). Although randomized controlled trials have demonstrated the efficacy of risperidone for aggression in these disorders, these trials are of short duration, typically six weeks or less (Aman et al.; Pringsheim & Gorman, 2012). It has been suggested based on placebo discontinuation studies that long-term treatment has limited benefits in the majority of children (Reyes, Buitelaar, Toren, Augustyns, & Eerdeken, 2006). Therefore, when antipsychotics are used for treatment of disruptive and aggressive behaviour, they should only be a short-term treatment strategy while behavioural and psychosocial approaches are being optimized.

A national educational curriculum for Canadian resident physicians in pediatrics and psychiatry based on Canadian and US guidelines on the treatment of disruptive and aggressive behaviour has been implemented to promote behaviour change among prescribers (Knapp et al., 2012; Pringsheim, Andrade, Doja, & Gorman, 2017; Rosato et al., 2012). In addition to enhancing clinician knowledge of information contained within guidelines, facilitation of parent knowledge to bolster decision making is another important strategy to increase collaborative and effective care. This is important because parents of children with behavioural problems may experience difficulty making decisions about treatment; they may have feelings of guilt and uncertainty regarding the available treatment options. ADHD is a highly heritable condition and is associated with low socioeconomic status, lower education (Klassen et al., 2004) and higher perceived stress (Combs, Canu, Broman-Fulks, Rocheleau, & Nieman, 2015). These factors could affect parents' ability to understand treatment options and make informed decisions. The assessment and treatment of children with disruptive and aggressive behaviour is complex and can be difficult to navigate, with a number of social, psychological, and medical interventions available from a variety of types of health care professionals.

Patient decision aids (PDAs) are tools designed to prepare and actively engage people in decision making. PDAs can educate people on the risks and benefits of different options

and ideally guide them to consider the value they place on the benefits versus the risks. One of the main objectives of PDAs is to help people to actively get involved in the decision-making process with their health care providers. The ideal PDA provides information on: (1) the disease and its treatment options; (2) benefits, harms, and uncertainties regarding treatment; (3) probabilities of outcomes tailored to the individuals risk factors; and (4) values clarification, which is the process involved in determining the importance of the various benefits, risks and options for the individual (Joseph-Williams et al., 2014). PDAs can be presented in different formats including printed materials, videos, and/or web-based applications and they may be administered before, during or after counseling. A systematic review of PDA intervention studies for people facing health treatment or screening decisions demonstrated high quality evidence that PDAs, when compared to usual care, improve people's knowledge regarding options, and reduce their decisional conflict related to feeling uninformed and unclear about their personal values (Stacey et al., 2014). Findings from this review also showed moderate evidence that PDAs, when compared to usual care, stimulate people to take a more active role in decision making and improve accurate risk perceptions when probabilities are included in decision aids (Stacey et al., 2014).

Decision coaching, provided by an individual, is an approach that can be used with decision aids to help facilitate decision making (Volk, Llewellyn-Thomas, Stacey, & Elwyn, 2013). Decision coaching is non-directive guidance provided by a trained health professional which supports patient decision making. This includes provision of information about the options, their benefits and harms, and helping the individual to clarify and articulate what matters most to them. A systematic review demonstrated that compared to usual care, decision coaching with a PDA improved patient knowledge and participation in decision making (Stacey et al., 2012).

While patient decision aids on the treatment of ADHD are currently available for use (Cincinnati Children's Hospital Medical Center, 2017; Husney, Romito, & Pope, 1995-2018) and have been shown to increase shared decision making with parents (Brinkman et al., 2013), the present study is a first step to create a PDA specifically on the management of disruptive and aggressive behaviour in children with ADHD, ODD and CD, in recognition of the unique needs of this population. The aim of this qualitative study was to explore the decisional needs of parents of children with disruptive and aggressive behaviour to inform the creation of a PDA. Our specific questions included:

1. What information do parents need to make decisions about the management of oppositional behaviour and aggression in children with DBDs?

2. What format would be most useful for a patient decision aid?
3. What are the barriers and facilitators to using a patient decision aid?
4. Is there a role for decision coaching in the decision making process?

Methods

Setting and Participants

A one-day meeting of researchers, community advocacy partners, and parents of children with aggressive and disruptive behaviour associated with a diagnosis of ADHD, ODD or CD was held in September of 2015 in Toronto, Canada. Purposive sampling was used to identify participants. The meeting included two health professionals with expertise in the treatment of disruptive and aggressive behaviour and psychotropic medication safety in children, and two health professionals with expertise in PDA development, decisional coaching, and knowledge translation. Three representatives from the Centre for ADHD Awareness Canada (CADDAC) and Tourette Canada participated in this meeting. CADDAC is a national, non-profit organization providing leadership in education and advocacy for ADHD organizations and individuals across Canada. Tourette Canada is a national voluntary organization dedicated to programs of education, advocacy, self-help and the promotion of research. A total of 11 parents of children (age range eight to 21) with disruptive and aggressive behaviour (three males, eight females, 30-60 years of age, all Caucasian) were recruited through CADDAC and Tourette Canada to participate in this meeting. Participants were given an honorarium of \$200 CAN to support travel expenses and time lost from employment.

Data Collection

The meeting consisted of a two-hour educational session on the assessment and management of aggressive and disruptive behaviour in children and on patient decision aids, followed by two concurrent focus groups to determine the decisional needs of parents. No data were collected during the two-hour educational session. During the educational session on patient decision aids, participants were given an overview of shared decision making, the purpose and structure of patient decision aids, and examples of condition-specific and generic decision aids were reviewed. Each one-hour focus group included seven participants plus a facilitator (TP or NJ). The focus groups were conducted using a semi-structured interview guide (see Table 1). Interview questions were focused on the four questions specified above. The focus group discussion was audio recorded and transcribed verbatim. Transcribed interviews were anonymized. The study was approved by the Conjoint Health Research Ethics Board at the University of Calgary. All participants provided informed consent.

Table 1. Interview guide

Main question	Possible probes
What are the decisional needs of parents and families?	-Do you need information on the range of available psychosocial and medical treatments available? -Do you need information on the effectiveness of individual treatments? In how much detail? -Do you need information on the potential risks of treatments? In how much detail? -Do you need information on the potential consequences of deciding not to treat the problem?
What formats would be most useful for a decision aid?	-A hardcopy or electronic document/pamphlet? -A smartphone or computer application? -Is there a role for one-on-one decisional coaching? -Who would be the best person to do this coaching? A parent peer? An advocacy/support organization? A health professional?
What are the potential barriers and facilitators to implementing a decision aid?	-What factors would make using a decision aid easy for parents? -When would using a decision aid be difficult for parents? -Is there a role for children and youth in the decision making process? How can we involve them?

Analysis

The focus group transcripts were analyzed using thematic analysis. The analysis proceeded according to the steps outlined by Braun and Clarke (Clarke & Braun, 2014). First, the research team familiarized themselves with the data, by reading and re-reading the data and making notes of initial ideas. Initial codes were generated in a systematic fashion across the entire data set, with collation of data relevant to each code. The team then searched for themes and collated codes into potential themes. Themes were reviewed in relation to the coded extracts and the entire data set. The themes were finally defined and named. Two members of the research team (EN and TP) each independently reviewed the data and performed the initial coding. The research team then met to discuss the coding, with any discrepancies discussed until consensus was reached. The team worked together to search for themes and to define and name these. NVivo11 software was used for the organization of the data.

Results

The following results outline the broad themes and subthemes that emerged from the thematic analysis (see Figure 1). These themes and subthemes include (a) decisional needs – treatment options and where to begin, availability, effectiveness of different treatment options, side effects, time, depth of information provided; (b) decision aid formats, and (c) accessibility – language, involvement of children, and dissemination. All data presented came from

interviews unless otherwise noted. Appendix 1 provides quotes from each theme and subtheme.

Theme 1: Decisional needs

Our recruitment strategy ensured that all participants had life experience as parents of children with DBDs. All of them agreed they had experienced some level of difficulty in making decisions for their child's treatment.

"It's a hard job but you want to at least think, okay, I'm making the most informed choice and the best choice at the moment."

Based on the interviews, we divided parents' decisional needs to 6 subthemes; treatment options and where to begin, accessibility and availability, effectiveness of different treatment options, side effects, time, and depth of information provided.

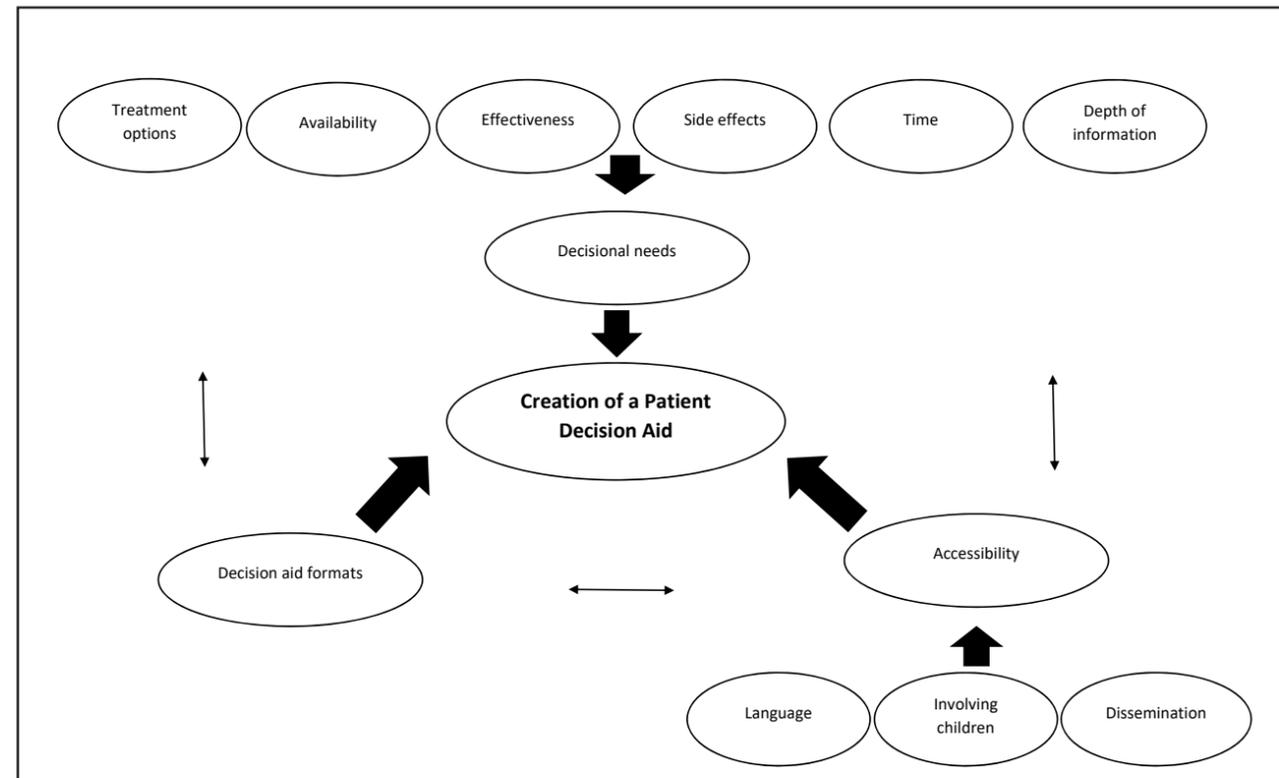
Treatment options and where to begin

Understanding treatment options and where to access relevant resources were participants' main priorities. They mentioned difficulties in deciding which option they should try first.

"You make a decision but you're not informed. They expect you to make a decision but they don't tell you your options"

"Even just steps, like what therapy to try first, I still don't know, you know, what therapy to try."

Figure 1. Themes and subthemes



“And sometimes you just think like, um, is it even worth using? The side effects that you hear about, and you don’t even know where to start. You start with behavior therapies, you start with meds, you do both together, where do you get the optimum results?”

Availability

Participants raised concerns about the availability and accessibility of treatment options. One participant mentioned trying to find available options in their area on the internet and another tried their local library to find accessible options. The other concern was cost – knowing which treatment options were covered by the public health care system and which options required supplemental health insurance or out of pocket payment.

“Do we need a psychiatrist, do we need a psychologist, do we need, you know, a specialist? It’s not just do we need this or that but where are they and how can I find them? Are they available in my area? And is it covered?”

“I walked into my local library and said, “my son has this, what do you guys have...?”

“I had to find it on the internet.”

Effectiveness of different treatment options

Almost all the participants mentioned they wanted to know the effectiveness of the different options based on research studies. They emphasized their need to know the short-term and long-term effects of their options.

“And if you’re trying to make decisions that are either medical or they’re pharmaceutical therapy or behavioral therapy, something more about the efficacy, likelihood of success.”

“Effectiveness, I was going to say short-term too, like short-term versus long-term, understanding how effectiveness can change over time and for me”

“Understanding what are the options, what are the medical but also psychosocial options and for both of these, what is the efficacy, what would be side effects, what would be the benefits and risks of each and, you know, I like also the comment about what about is there evidence regarding the long-term outcome of making these different choices”

“How long will it take before I see the treatment or whatever approach we’re taking, therapy, work? How long and what happens if it’s not going well, like so

“I’ve started to take this medication and then all of a sudden I think I’m having symptoms or there’s something wrong, like what do I do then?”

“Pros and cons to each kind of treatment option long-term, proven, meaning yeah, is there, you know, studies or not studies or evidence-based”

Two of the participants stated that they thought doctors provide their personal opinions about different treatments. We talked to them during the educational session about evidence-based guidelines and how guidelines attempt to take the opinions out of the treatment actions.

“Like every doctor has their own personal opinion and it shouldn’t be a personal opinion, it should be fact-based and this is a fact.”

“For treatment options, you’re saying like what helps make a decision. I think the other thing as a parent that I found hard was like, yes, I like to read a lot, like, and I do trust my doctor but it’s one opinion, like that’s what you said, right? So, so many of us, it’s kind of like, well, for different treatments people say, oh, go for another opinion.”

Side effects

Participants were interested to know the side effects of different medications, and what they could do to mitigate the side effects and manage them when they occur. One of the participants also emphasized the importance of regular appointments to track adverse effects.

“What’s the likelihood of a particular side effect?”

“I also want to know, what will you do, like are there things I can do to minimize or mitigate the risk and what happens if I become that statistic where the risk happened to me?”

“For me that’s good, you know, that’s good enough. They’re checking, they’re keeping an eye on how everything is going. I think that’s the whole thing. They’re not just sending you off with a bottle of pills and saying, alright, see you later, you know. I mean I think that whole idea about checking, you know, that makes it less scary, the fact that there’s somebody, you know, someone who’s going to come back and see me in 2 weeks to see if everything is okay.”

Time

Almost all the participants had concerns regarding the short duration of their appointments. They commented on not having enough time to understand every option and make an informed decision during those appointments.

“Yeah, and they’re like, okay, what are you gonna do? Let me write, and you’re like, you don’t have time to absorb a) the diagnosis, b) the little bit of information

that you do have, and if you say, well, can I have another appointment next week? Well no, I’m booked up. You can come back in 4 months.”

“I think the other thing you need is time. We don’t have time. You’re in that specialist’s office for, you have a 15 minute period of time...”

“To me and I’m, well he’s talking and I’m not really absorbing anything he’s saying because I’m just sitting there and I’m okay, now what do I do, what do I do, what do I do, and there’s no time to absorb it.”

“Yeah, you’re put on the spot, like I remember looking at my husband and going, what are we gonna do? We have like, you know, 5 seconds to decide. I felt like I was in a Minute to Win It, you know, like...”

Depth of information provided

Most parents agreed that the depth of information provided should be optimized. They emphasized that they want to know necessary details to be able to make their decision wisely. Parents acknowledged that knowing every single detail is not necessary and may cause differing levels of stress.

“A lot of times when you look up medications...you get your basic information but then you get people who are, it’s like, you know. It scares the pants off them but it’s not good information.”

“For me, I like to know a lot but that’s just my sense of control and it doesn’t freak me out but I also know other parents, they’re like, you know what, now that I’ve heard all that, like it’s, you know, they don’t want that.”

“Something that isn’t too text or prose heavy because if you have to read, you know, pages and pages and pages, you’re not going to want to do it.”

Theme 2: Decision aid formats

The main decision aid formats that were appealing to parents were decisional coaching and web-based tools. Most parents felt that decisional coaching would be helpful. They had different opinions about who would be the right person to do the coaching. They mentioned parents with similar experiences and people with medical backgrounds and special training as potential coaches.

“You know, there are sometimes like parent peers and, you know, you have more experience than even myself because, you know, you live with this everyday and all that, you’re at the forefront.”

“Well I think they definitely need to have training in crisis, yeah, and also in ADHD”

All participants agreed that an online tool would be a useful format for a decision aid. Parents also suggested having pamphlets that guide parents through the decision making process and using diagrams to communicate information.

Theme 3: Accessibility

We divided accessibility into three subthemes: language, involving children and dissemination.

Language

Most parents suggested that the language of the decision aid should be in layman's terms with definitions of medical terms.

"You have to remember that you could be dealing with parents who are on social assistance, maybe not a lot of education. They may, themselves, have learning disabilities, to someone who could be a PhD so you have to kind of go in the middle somewhat."

"Sometimes we would use the medical term and then do a little bracket, so the parents at the same time you are giving it to them in a parent-friendly way, they're also picking up medical terms."

Involving children

We asked parents the best way to involve children in the decision-making process. Many of them suggested creating applications specifically for children. They also suggested using avatars.

"You know, I think they love tech stuff, a lot of them, they all use iPads now and stuff so I think they are the more app generation."

Dissemination

We asked parents the best way to disseminate the decision aid to ensure that it reaches the families who need it. The main suggestions were to inform physicians and health care professionals treating families with these disorders, and using different forms of media, such as the press. They also felt that all materials should be made available free of charge.

Discussion

Based on the information gathered in our focus group interviews an ideal decision aid for parents of children with ADHD and disruptive and aggressive behaviour would include information on all treatment options (medications and behavioural therapies) and how treatment can be sequenced, information on effectiveness and adverse effects (including the number needed to treat and harm), where treatments are available and cost. Information needs to be provided in adequate depth for decision making, and while in layman's terms, provide opportunities to learn medical

terms. Given the need for information on availability of therapeutic options, and that many of the first-line recommended treatments are psychosocial rather than medical interventions, a web-based tool would allow information to be customized by geographic location and continuously updated. A website with the desired information, an online decision support system, and local peer coaches available by telephone, may help meet the decision needs of parents. The developed site should include dedicated space for information for children. Dissemination should target health care providers and patients and their families and can likely be achieved through collaboration with community and professional organizations.

The themes which arose in the two focus groups were very similar, and there were no unexpected findings. As anticipated from the literature on ideal PDAs (Joseph-Williams et al., 2014) parents wanted information on ADHD and its treatment options; benefits, harms, and uncertainties regarding treatment; and the probabilities of outcomes tailored to the individuals risk factors. The only theme that was not a major topic of discussion in our focus groups was values clarifications. Parents emphasized the need for time to make informed decisions, and how difficult this was to do during a short appointment, with limited opportunities for a second appointment within a reasonable time period. This suggests that a patient decision aid for the management of disruptive and aggressive behaviour would ideally be used prior to appointments at anytime during the clinical course, to allow parents to have some knowledge prior to making a treatment decision with their physician or other health care professional.

Treatment decisions for parents of children with behavioural disorders are difficult. In a qualitative study by Brinkman and colleagues, parents of children and adolescents with ADHD answered questions about decision making, information sharing and sources of conflict and uncertainty (Brinkman et al., 2009). The researchers found that parents experience a complex variety of stressors as they decide how to help their child with ADHD. Parent discussed feelings of self-doubt regarding their parenting skills, and often blamed themselves for their child's difficulties. Parents described stressful conflicts with their child on a routine basis over simple daily activities, and stress related to the amount of effort required to parent their child and the ineffectiveness of those efforts. Parents experienced stress from conflicts between mothers and fathers regarding their child's behaviour and appropriate therapy, as well as from pressure from school personnel to take action regarding their child's behaviour.

There is literature to support the use of shared decision making and patient decision aids for children and families affected by ADHD, suggesting such strategies may have a positive impact in those with disruptive and aggressive behaviour. A qualitative study which compared how parents

and clinicians understand shared decision making in ADHD found that while both groups viewed shared decision making favorably (Fiks, Hughes, Gafen, Guevara, & Barg, 2010), they conceptualize shared decision making differently. Parents conceptualize shared decision making as a partnership between equals, with the clinician having the role of presenting all available treatment options, and the parent providing in-depth knowledge of the child and their behaviour. Parents reacted negatively to clinicians who prescribed medications without providing an equal share of information on alternatives. In contrast, the majority of clinicians interviewed viewed shared decision making as a way to get parents to comply with their recommended treatment. This finding suggests that the use of a patient decision aid, which provides an un-biased overview of all available treatment options, may help families of children with disruptive and aggressive behaviour obtain the information they need to facilitate decision making. Fiks' and colleagues' study also highlighted how real world barriers limit the consideration of evidence-based therapies in ADHD, especially the use of behavioural therapies, which are expensive and therefore not accessible for many families (Fiks et al., 2010). This will also be an issue for the treatment of disruptive and aggressive behaviour. A subsequent study examining the effects of a shared decision making intervention with parents of children newly diagnosed with ADHD found that compared to controls, parents receiving the intervention were more involved in shared decision making, more knowledgeable about treatment options, and less conflicted (Brinkman et al., 2013).

Our study was limited by a small sample size, with all Caucasian participants confined to one large metropolitan city. It is possible that the group setting prevented some parents from participating in the focus groups, or that parents of children with more severe symptoms were more likely to participate. It was surprising that values clarification was not identified as a major theme by participants in our focus groups. This could be related to the manner in which values clarification was introduced to participants and whether this concept was understood adequately by them, or due to the directive nature of the interview guide which may have prevented more active exploration of the topic. Future work to assess the transferability of the themes identified to a larger group of parents could include online surveys disseminated through patient advocacy organizations. We chose to provide an educational session to participants prior to the focus group meeting. It is possible that this may have influenced the views of participants.

In conclusion, the themes generated from the focus groups suggest that a patient decision aid for parents with children with ADHD and disruptive and aggressive behaviour should follow the general recommendations for best practices for the creation of patient decision aids (Joseph-Williams et al., 2014). Specific information on the regional availability of non-medical treatments will be especially

helpful for parents to navigate services and service providers. Consideration should be given as to how the concept of values clarification is introduced to families.

Acknowledgements / Conflicts of Interest

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Appendix 1. Themes, subthemes and sample quotes to illustrate them		
Main theme	Subtheme	Sample quotes
Decisional needs	Treatment options and where to begin	-“You make a decision but you're not informed. They expect you to make a decision but they don't tell you your options” -“You don't even know where to start. You start with behavior therapies, you start with meds, you do both together, where do you get the optimum results?” -“Who do you see? A doctor? Because there's different, and when I was researching for my son to find therapy for him, there's such a wide variety and some of these people are just therapists. They've got no medical training, they've got no designation...” -“Even just steps, like what therapy to try first, I still don't know, you know, what therapy to try” -“Understanding what are the options, what are the medical but also psychosocial options and for both of these” -“The different options, psychosocial, medical, what are the options for each, what are the benefits and harms of each and to what extent, how come and so on” -“And is it covered” -“Where to go first or what you were most interested in trying first” -“Understanding if it is available” -“It's not just do we need this or that but where are they and how can I find them? Are they available in my area?” -“I had to find it on the internet” -“I walked into my local library and said; my son has this, what do you guys have, like what kind...” -“And is it covered.”
	Availability	-“And if you're trying to make decisions that are either medical or they're pharmaceutical therapy or behavioral therapy, something more about the efficacy, likelihood of success” -“What is the efficacy” -“The effectiveness of each treatment” -“Effectiveness, I was going to say short-term too, like short-term versus long-term, understanding how effectiveness can change over time and for me” -“Pros and cons to each kind of treatment option long-term, proven, meaning yeah, is there, you know, studies or not studies or evidence-based” -“Sort of the benefits and risks of each and, you know, I like also the comment about what about is there evidence regarding the long-term outcome of making these different choices”
	Effectiveness of different treatment options	-“What's the likelihood of a particular side effect” -“What would be side effects” -“I also want to know, what will you do, like are there things I can do to minimize or mitigate the risk and what happens if I become that statistic where the risk happened to me” -“For me that's good, you know, that's good enough. They're checking, they're keeping an eye on how everything is going. I think that's the whole thing. They're not just sending you off with a bottle of pills and saying, alright, see you later, you know, I mean I think that whole idea about checking, you know, that makes it less scary, the fact that there's somebody, you know, someone who's going to come back and see me in 2 weeks to see if everything is okay.”
	Side effects	

continued

Appendix 1 continued		
Main theme	Subtheme	Sample quotes
	Time	<p>-“I think the other thing you need is time. We don't have time. You're in that specialist's office for, you have a 15 minute period of time...”</p> <p>-“Yeah, and they're like, okay, what are you gonna do? Let me write, and you're like, you don't have time to absorb a) the diagnosis, b) the little bit of information that you do have, and if you say, well, can I have another appointment next week? Well no, I'm booked up, you can come back in 4 months. So you're kind of like.”</p> <p>-“Yeah, you're put on the spot, like I remember looking at my husband and going, what are we gonna do? We have like, you know, 5 seconds to decide. I felt like I was in a Minute to Win It, you know, like...”</p> <p>-“To me and I'm, well he's talking and I'm not really absorbing anything he's saying because I'm just sitting there and I'm okay, now what do I do, what do I do, what do I do, and there's no time to absorb it.”</p>
	Depth of information provided	<p>-“I was going to say when you were talking about a lot of times when you look up medications and you get, I mean you get like, you know, you get your basic information but then you get people who are, it's like, you know, it scares the pants off them but it's not good information.”</p> <p>-“Yeah, how much do you want because then they're asking. For me, I like to know a lot but that's just my sense of control and it doesn't freak me out but I also know other parents, they're like, you know what, now that I've heard all that, like it's, you know, they don't want that.”</p> <p>-“I think the doctor, because they ask you that, because I do think some people, I've heard that where they're like, I don't want to know maybe like because you're going to send someone else's anxiety, like it's not like she doesn't want to know but you're right, I don't know how you regulate that.”</p>
Decision aid formats		<p>-“One-on-one decisional coaching”</p> <p>-“I like coaching, just...”</p> <p>-“The app would be kind of a good decision aid but it sounds like it would also be helpful if you could track...”</p> <p>-“Electronic format, an app”</p> <p>-“Website the app can be downloaded”</p> <p>-“Like a little webinar-type thing”</p> <p>-“App idea, the online idea”</p> <p>-“Or a video component, like I'm not always a big fan of video but I know that's big for a lot of people now, like rather than just pulling up the blanks, some people prefer to, you know, have someone walk them through or have a little video, like it has to be short, the 2 minute video clip.”</p> <p>-“Happy face diagrams”</p> <p>-“Avatars, like artificial intelligence”</p> <p>-“Hard copies”</p> <p>-“Having both parents be able to enter information”</p> <p>-“I'm just thinking, having a decision, one of those decision-making tools accessible through the internet where the father and mother can do them independently, put in their things and then [cross talk].”</p>

continued

Appendix 1 continued		
Main theme	Subtheme	Sample quotes
Accessibility	Language	<p>-“Something that isn't too text or prose heavy because if you have to read, you know, pages and pages and pages, you're not going to want to do it.”</p> <p>-“Well also if it could have a pause or save.”</p> <p>-“Go up in text size or go down.”</p> <p>-“You have to remember that you could be dealing with parents who are on social assistance, maybe not a lot of education. They may, themselves, have learning disabilities to someone who could be a PhD so you have to kind of go in the middle somewhat.”</p> <p>-“Sometimes we would use the medical term and then do a little [cross talk] bracket, so the parents at the same time you are giving it to them in a parent-friendly way, they're also picking up medical terms.”</p> <p>-“Yeah, it has to be in layman's terms.”</p> <p>-“It's free, a free app.”</p> <p>-“Free at first and then you like, then I don't have a problem paying for it”</p>
	Involving children	<p>-“You know, I think they love tech stuff, a lot of them, they all use iPads now and stuff so I think they are the more app generation [inaudible segment].”</p> <p>-“They like they apps, very apps.”</p> <p>-“More electronic, apps, avatar, like playing things, you know, are more appropriate for them.”</p> <p>-“Avatars, like artificial intelligence”</p> <p>-“Their own questionnaire”</p>
	Dissemination	<p>-“The first steps would be to educate the physicians about it and that it exists so they can [cross talk].”</p> <p>-“Bell Media in Syracuse, they do [inaudible segment], they donate.”</p> <p>-“The media”</p> <p>-“I have a different answer for you, it's press.”</p>