Letter of Intent

Adolescent Perceptions and Motivations of Psychosocial Treatments for Attention-Deficit/Hyperactivity Disorder: A Qualitative Study

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Attention-Deficit/Hyperactivity Disorder (ADHD) is a chronic and pervasive developmental disorder that is not restricted to the childhood years (Young & Amarasinghe, 2010). Teens that are inattentive and/or impulsive to a degree that is markedly deviant for their age, and result in impairments in major life activities may currently be diagnosed with ADHD (Barkely, 2004). Diagnoses of ADHD are commonly made in childhood, but often persist across developmental phases and estimates of 50%-80% will continue to have the disorder in adolescence (Barkley, 2004). The clinical presentation of ADHD in adolescence appears to become more complex in potential impairments and more complicated and difficult to manage with treatment due to teens’ increasing independence and developmental characteristics. Adolescents with ADHD are a high risk population that including many individuals with unique treatment needs, which may benefit from psychosocial treatment.

Problem Statement

Adolescence is a period in which difficulties with maintenance and efficacy of treatments for ADHD are present. Developmental characteristics, perceptions, and motivation of adolescents may potentially contribute to the success of psychosocial treatment. Although ADHD is often chronic and results in increased risk and potential pernicious outcomes, adolescents are most likely to disengage from services, and only a minority receive treatment (Smith et al., 2000; Young & Amarasinghe, 2010). The reasons for low rates of treatment of adolescents with ADHD are unclear, and researchers and practitioners continue to be challenged by the pervasive nature of ADHD, its heterogeneity in symptom presentation, and comorbid conditions (Molina et al., 2009; Young & Armarasinghe, 2010). Potential reasons for lack of treatment are reluctance to participate in treatment and low motivation (Smith et al., 2000; Molina et al., 2009). This letter of intent proposes to address the key research questions; what are current adolescent perceptions of ADHD and psychosocial treatments, and what motivates adolescents
to participate in treatment. To address the research questions, this letter of intent introduces a qualitative study to investigate information and insights from the adolescent perspective that will contribute to emerging research in the field, and enhance efficacy of psychosocial treatments.

**Rationale**

Adolescents with ADHD are often at-risk for a multiple of difficulties and life impairments such as: low self-esteem, family conflicts, academic difficulties, comorbid personality/behaviour disorders, substance use disorders, increased sexual and driving risks, and poor peer relationships, (Barkley, 2004; Crockett, Moilanen, Raffaelli, & Randall, 2006; Edwards, Barkley, Laneri, Fletcher, & Metevia, 2001; Evans, Serpell, Schultz, & Pastor, 2007; Firmin & Phillips, 2009; Smith, Waschbusch, Willowby, & Evans, 2000; Young, Heptinstall, Sonuga-Barke, Chadwick, & Taylor, 2005) In addition, adolescents have to cope in less structured but often more demanding environments, and unfolding developmental stages with new challenges that have particular difficulties for adolescents with ADHD (Young & Amarasinghe, 2010). Professionals must keep in mind that adjustments must be made to treatments to address adolescents’ psychological and physical stages of maturity, their developing sense of autonomy, and their emergence into the larger community (Barkley, 2004). Adolescence is typically marked by greater cognitive abilities with increased ability to solve problems. Consequently, adolescents are more self-conscious, better able to predict their own behaviour, and better able to evaluate available strategies, which may have an impact on the effectiveness of psychosocial treatments (Smith et al., 2000). As teens have an increasing capacity and desire for self-determination, there is greater reliance on the willingness of the teen to cooperate with treatment recommendations. As noted by Firmin and Phillips (2009) in order to fully grasp the effects of this disorder, analyzing data gathered directly from those that are affected by it will contribute to a better understanding and treatment of adolescents with ADHD. This study allows adolescents to have input into the types of psychosocial treatments that may result in modifications to standard methods of treatments.
Literature Review

Current research in the field is limited regarding psychosocial treatment efficacy for adolescents with ADHD as the majority of studies are conducted in children (Barkley, 2004; Crockett et al., 2006; Edwards et al., 2001; Evans et al., 2007; Firmin & Phillips, 2009; Knight, Rooney, & Tuscano, 2008; Smith et al., 2000; Young & Amarasinghe, 2010). A thorough literature review was conducted previously by the author on the topic of psychosocial treatments for ADHD which demonstrated a lack of studies for adolescents and difficulties generalizing results to the adolescent population that provided the source data and basis for developing this research (Appendix A). The majority of psychosocial treatments for adolescents are extrapolated from the existing literature for children and further scientific study of ADHD and treatment in teens is needed. It is noted that within the field a clear construct of adolescence is lacking which will contribute to further research limitations (Smith et al., 2000). Generalizations of the findings from research for children to adolescents with ADHD are problematic when considering the differences in presentation of adolescent ADHD.

Adolescence and ADHD

Although research suggests that the adolescent stage of ADHD is sufficiently continuous with the childhood stage as there is no evidence that ADHD is qualitatively different from the disorder in children; there are differences in presentation and stages of development exist that create implications for treatment and further study (Barkley, 2004; Molina et al., 2009; Smith et al., 2000; Young et al., 2005). The primary differences include: declines and increases in symptom severity (hyperactive behaviour decreases while persistence/self-control/organization difficulties increase), changes in neurological and hormonal development that affect symptom expression, more elaborate cognitive domains (verbal working memory, internalized speech, emotional self-control, and cross-temporal organization) that become increasingly affected by the disorder than in childhood, risk of comorbid disorders (substance use disorders, conduct disorder, and depression), and new domains of potential
impairments such as sexual or driving risks (Barkley, 2004; Smith et al., 2000). The tendency to treat adolescents with ADHD as children discounts the fact that there are many differences between adolescence and childhood that may be clinically relevant to the treatment of ADHD (Smith et al., 2000). As adolescents become more autonomous from parents and teachers and spend increased time with peers and in unsupervised community settings, problems in motivation to treatment adherence arise; and motivational ‘prostheses’ that are essential for continued treatment success are difficult to provide (Barkley, 2004). Elaboration of developmental considerations as they interact with ADHD is in its early stages, and is informed by the interaction of developmental theory and theories of ADHD (Smith et al., 2000).

Psychosocial Treatments and Adolescence

The theoretical model of ADHD proposed by Barkley (2004) suggests that ADHD is not a result of a lack of skill, knowledge, or information; instead it is a disorder of performance and requires ongoing treatment. Efficacious psychosocial treatments for ADHD are maintained over time and reinforced in natural settings (Barkley, 2004). Psychosocial treatments are used to cue the use of skills at key points of performance in natural settings, and to motivate responses for success at assigned tasks (Antshel & Barkley, 2008). Psychosocial interventions play a prominent role in the management of ADHD for the following key reasons: lower doses of stimulant medications is often a result when combined with psychosocial treatments, parents are often supportive of this form of treatment, stimulant medication is not effective for all individuals and is associated with negative side effects, there is a possibility that medication effects may be different before and after puberty, and there is evidence that peer and family relationships and academic achievement can benefit from psychosocial interventions (Antshel & Barkley, 2008; Smith et al., 2000). Psychosocial treatments have documented efficacy for management of ADHD in children (Appendix A). The limited available research on efficacious psychosocial treatment for adolescents with ADHD suggest some benefits of the following approaches:
behavioural parent training or family training programs that include modifications for adolescent
development to address family conflicts, academic accommodations, classroom behaviour modification
methods, special education support, and interventions for comorbid symptoms (Barkley, 2004; Smith et
al., 2000; Young & Amarasinghe, 2010). Cognitive skills techniques and greater involvement of teens in
the treatment process may address peer-related and achievement related issues and meet the needs for
autonomy (Young & Amarasinghe, 2010). Importantly, treatments should be modified at key
developmental transitions to reflect the behaviours that are most impaired at the time to ensure that the
goals and methods of treatment are meaningful and motivating for the individual (Smith et al., 2000;
Young & Amarasinghe, 2010). The limited data specific to adolescents is a serious limitation to the
understanding of treatment of ADHD because the presentation and treatment of psychopathology often
differs as a function of age (Smith et al., 2000). Currently there is insufficient research to inform
practitioners about which psychosocial interventions should be provided for this age group (Young &
Amarasinghe, 2010). Treatments may need to target motivational variables to encourage adolescent
participation and maintenance.

Methods

Procedures

The qualitative method chosen to investigate the perceptions and motivations of adolescents with
ADHD for this study is a focus group. This method was chosen given the conceptually rich information
for detailed psychological descriptions for adolescents’ experiences and perceptions of psychosocial
treatments that will be available from the open-ended focus group questions (Appendix B). Participants
will be provided instructions for the focus group (Appendix C), and the meeting will be conducted in a
non-threatening environment with no previous treatment associations (a meeting room at the local
community center will be confirmed). The meeting should last approximately 90 minutes depending
upon the level of participation and detail of answers. In consideration of the difficulties associated with
motivation and participation of this target group, incentives for participation will be provided that include Itunes gift cards ($10.00 each) and a chance to win an Ipod (draw at the end of the focus group meeting) for their participation at the completion of the meeting.

A research team from the School and Applied Child Psychology Department at the University of Calgary will be recruited to provide expert review, application for grants to fund costs associated with the study, data analysis, and further assistance in the study. This research team will include the author (Masters of Education student), and potentially other Master’s students, Doctoral students in psychology, or department of applied psychology faculty members depending upon availability and volunteer participation. Specifically, experience in child psychopathology (ADHD), adolescent developmental theory, and qualitative research would be sought out for this research team. For this study only one focus group will be conducted, however it is expected that information from the results will provide the basis for further focus groups, interviews, or surveys on the topic.

Ethical Considerations

Formal ethics approval for this research will be sought from the Conjoint Faculties Research Ethics Board (CFREB) through the Research Services department at the University of Calgary (U of C). Both parents and adolescent participants will be provided a full description of the research and details of their participation, additionally both will be required to complete an informed consent form developed using the template from the U of C Research Services (Appendix D). The issue of confidentiality will be addressed during participant instructions (Appendix C), and participants may withdraw their participation at any time. It is expected that participation in the study is at a low level of risk; however debriefing will be accessible through the research team where referrals to private and community health care professionals will be made available. Demographic and identification information collected will not be disclosed outside of the research team, or disseminated in the analysis and results. Participants will be collectively referred to as ‘participants’, ‘teens’, or ‘one individual’ in the final report. Data from
the focus group will be reviewed only by the research team, and stored by the author in a secure location. Results will be provided to interested participants, and involvement in follow-up studies is voluntary.

**Participants**

Participants will be recruited by referral through local schools, doctors, counsellors, and psychologists. Recruitment flyers will be developed with the assistance of the research team and made available at the recruitment locations. Professionals at the sites will provide potential participants the information regarding the study at which time the parents may contact the research team for initial screening. If the participants meet eligibility criteria they will be contacted for further discussion regarding the details of the research. Participation is voluntary and consent by parents and participants will be obtained prior to further involvement. The number of participants needed to conduct the focus group will be 6 to 12 adolescents, which will be a manageable group for the meeting and should provide enough data to begin to explore the research questions. Future focus groups may be developed to provide additional data or explore alternate themes related to this research.

Inclusion criteria requires that participants: (a) are aged between 15 and 18 years, (b) have a current diagnosis of ADHD as per the Diagnostic and Statistical Manual of Mental Disorders (4th ed., text rev.; DSM-IV-TR; American Psychiatric Association, 2000), (c) do not meet diagnostic criteria for pervasive developmental disorder, and (d) are either currently or previously involved in psychosocial treatment(s) with a duration of 12 weeks minimum. Demographic characteristics of sex, age, ethnicity, type of ADHD, comorbidity (if present), use of stimulant medication, special education involvement, and family constellation will be collected and stored for potential future comparison analysis.

**Data Collection and Analysis**

Participants will be asked to complete the consent forms and provide demographic information prior to participating in the focus group discussion. The focus group will be lead by the author and
another member of the research team, with one member conducting the group and the other summarizing participant responses, body language, and emphasis or intensity of comments. The focus group will be audio-taped, and fully transcribed, and then analysed by the research team. The data will be evaluated using a coding method that divides material into coherent units and theme analysis. Additional coding strategies for assessing the data for repeated words, constructs, and patterns in the responses will be utilised for further examination. Computer software such as NVivo will assist in organizing the coded data. Final themes will be linked back to codes and original data for cross checks and consensus regarding theme analysis within the research team. Qualitative responses will be selected to include in the results for descriptive purposes.

**Potential Limitations**

Several limitations may be associated with this research. The small sample size makes it difficult to draw concrete conclusions or make generalizations about the entire target population. There is the potential for the focus group to have an unequal gender representation as more males than females are diagnosed with ADHD, and it is possible that adolescent female presentation of ADHD is different which may require further study (Young et al., 2005). The definition of adolescence within this study is arbitrary, and may not adequately reflect developmental stages of adolescence. Psychosocial treatments were explored in general which may not adequately reflect perceptions for specific treatment options. Future study may involve examination of adolescent perceptions and motivations of particular psychosocial treatments for more in-depth information and additional insights. The use of self-report data from adolescents with ADHD may also have inherent problems that include: low participation or commitment to answers, self-reporting bias, possible ambivalence regarding ADHD and treatment, difficulties associated with information processing and self-monitoring, and participant accounts may differ from parental or teacher perspectives of their experiences. Group dynamics within the focus group may also affect participants’ answers to questions when considering the effects of peer influence.
and identification. A future consideration may be to repeat this study in an on-line meeting to provide participants increased anonymity. To strengthen findings, additional studies are needed that include examination of multiple variables within adolescents with ADHD, samples taken from multiple locales, or replication studies are additional areas of research that are needed.

Potential Implications

Current research shows that there are high rates of treatment attrition within this age group that contribute to continued impairments and negative life outcomes. Insights gained from the data analysis regarding perceptions and motivations may contribute to providing ongoing and successful psychosocial treatment, and overcome traditional barriers associated with adolescence. In addition, insights into why low rates of treatment exist for this age group may contribute to an understanding of how to identify what treatment is most effective for adolescents with ADHD, and in what circumstances. Information may provide professionals with information to modify current psychosocial treatments to encourage participation, adherence, and maintenance for increased efficacy. It is hoped that tools for adolescents to use autonomously or identification of motivational variables to assist and manage treatment may be developed as a result of the rich information from this research.

It is expected that information and insights gained through the focus group may provide the development of questions for a series of further focus groups as a whole or into subgroups (e.g. female/male, type of ADHD), survey development, or personal interviews for additional examination of the research questions. Results may contribute to the emerging research on adolescent ADHD by adding detailed psychological information in addition to existing isolated trait and symptom knowledge. In addition, new or alternative areas of study may be identified during this research for further exploration.

Potentially the participants in the focus group may benefit through the process of self-reflection, and sense of ‘community’ with others with similar issues and diagnoses. The influence of peers for this age group often has impact on perceptions and behaviours, and may result in learning strategies from
other’s successes, or developing a support group within their community. Participation may also contribute to a deeper understanding of how ADHD affects participants’ lives and create a sense of responsibility or motivation to become involved in their own treatment plans and decisions.
References


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Appendix A

Literature Review Source Data References


Appendix B

Focus Group Questions

1. What is ADHD like for you?

2. How does ADHD affect your life?

3. How do you feel about treatment?

4. What type of treatment works best for you? Why?

5. What in your life affects your participation in treatment?

6. How would you like to deal with ADHD in your life?
Appendix C

Participant Instructions

Introduction to Discussion

“We should first offer some guidelines for how the group will be conducted. It is important for you to know that we feel there are no right or wrong answers; it is important for you to share your views and opinions, not what you think we want to hear. We would appreciate it each of you took turns in answering the questions and try not to interrupt while others are speaking. We would like to emphasize that we are here to learn from you and would really like to know your thoughts on these questions. We are happy to answer questions if something is unclear or if you would like a question repeated. Also, we want to respect everyone’s confidentiality so we ask that the things said in this room remain here. Does anyone have any questions?”

Open-ended Focus Group Questions and Discussion

“We would like to thank you for your participation, we will be available after the meeting for discussion if you have any further questions or concerns.”

Draw prize and gift cards
Appendix D

Informed Consent Form

University of Calgary

Name of Researcher, Faculty, Department, Telephone & Email:

Dianne L. Ballance, Faculty of Education, School and Applied Child Psychology, (250)308-0221, ballads@telus.net

Title of Project:

Adolescent Perceptions and Motivations of Psychosocial Treatments for Attention-Deficit/Hyperactive Disorder

This consent form, a copy of which has been given to you, is only part of the process of informed consent. If you want more details about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

The University of Calgary Conjoint Faculties Research Ethics Board has approved this research study.

Purpose of the Study:

The purpose of this study is to investigate information and insights from the adolescent perspective regarding perceptions and motivations of psychosocial treatments. Using a qualitative method of investigation a focus group meeting will be conducted to collect detailed information to contribute to research and current professional practice to enhance the efficacy of psychosocial treatments for adolescents with Attention-Deficit/Hyperactivity Disorder (ADHD).

Adolescents between the ages of 15 and 18 with a current diagnosis of ADHD that are currently or previously been involved in psychosocial treatment, were recruited through flyers within the local community or professional referrals. If you have been provided this consent form you and your parents have shown an interest in participating in this study. Please consider this form an invitation to participate.

What Will I Be Asked to Do?

Your participation for this study includes one focus group meeting with a group of 6 to 12 other adolescents to answer six open-ended questions regarding your perceptions and participation of ADHD and psychosocial treatments. It is expected that the meeting will last approximately 60 to 90 minutes, and is located in the community centre meeting room. The meeting will be conducted by two members of the research team and will be audio-taped and subsequently transcribed for analysis. Your participation is voluntary, and you may refuse to participate altogether or you may withdraw from the study at any time. A member of the research team will be available for contact prior and after the meeting for questions, concerns, and support. Results will be provided to you at the completion of the research upon your request.

What type of Personal Information Will Be Collected?

Should you agree to participate, you will be asked to provide your gender, age, ADHD subtype, ethnicity, any comorbid diagnoses, use of stimulant medication, special education involvement, and family constellation information.

There are several options for you to consider if you decide to take part in this research. You can choose all, some or none of them. Please put a check mark on the corresponding line(s) that grants me permission to:
I grant permission to be audio taped: Yes:____ No:____
You may use my name during the focus group meeting: Yes:____ No:____
I wish to remain anonymous, but you may refer to me by a pseudonym: Yes:____ No:____
The pseudonym I choose for myself is: _____________________________________________
You may quote me: Yes:____ No:____
You may contact me for follow-up studies: Yes:____ No:____

Are There Risks or Benefits if I Participate?

No foreseeable risk is associated with your participation, and a research team member will be available to you at any time should you feel you need support as a result of participating.
Participants will receive an Itunes gift card worth $10.00 or a chance to win an Ipod during a draw at the end of the focus group meeting.
As a result of the discussion you may become aware of personal or other’s insights into management of ADHD, or develop a supportive relationship with a peer.

What Happens to the Information I Provide?

Participation is completely voluntary, anonymous and confidential. You are free to discontinue participation at any time during the study. No one except the research team will be allowed to see or hear any of the answers to the focus group questions and audio-tape. Only group information will be summarized for any presentation or publication of results. The questionnaires are kept in a locked cabinet only accessible by the researcher and her supervisor. The anonymous data will be stored for three years on a computer disk, at which time, it will be permanently erased. Direct quotes will not be associated with names, and will only be referred to as ‘teen’, ‘participant’, or ‘individual’. All information during the meeting is confidential, and participants agree to maintain confidentiality of all members after the discussion. If you decide to withdraw from the research your information will be eliminated from the analysis, and either destroyed or returned to you on your request.

Signatures (written consent)
Your signature on this form indicates that you 1) understand to your satisfaction the information provided to you about your participation in this research project, and 2) agree to participate as a research subject.

In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from this research project at any time. You should feel free to ask for clarification or new information throughout your participation.

Participant’s Name: (please print) ________________________________________________
Participant’s Signature: ___________________________ Date: __________________________

Parent/Guardian’s Name: (please print) __________________________________________
Parent/Guardian’s Signature: ___________________________ Date: ______________________

Researcher’s Name: (please print) ________________________________________________
Researcher’s Signature: ___________________________ Date: __________________________
Questions/Concerns

If you have any further questions or want clarification regarding this research and/or your participation please contact:

Dianne L. Ballance
School & Applied Child Psychology, Faculty of Education

Ph# (250)308-0221 Email: ballads@telus.net

If you have any concerns about the way you’ve been treated as a participant, please contact the Senior Ethics Resource Officer, Research Services Office, University of Calgary at (403) 220-3782; email rburruow@ucalgary.ca

A copy of this consent form has been given to you to keep for your records and reference. The investigator has kept a copy of the consent form.