

Predicting Decisions Regarding ADHD Medication Using the Theory of Planned Behaviour

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Supervisor: Kevin Thomas

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Word count:

Abstract: 166

Main Body: 8518

Turn-it-in percentage:

Abstract

Many children with ADHD use medication to treat the symptoms of their disorder. The parents of these children typically have the final say in determining whether medication use should be initiated and continued, but many factors contribute to the outcome of this decision. This research used the theory of planned behaviour (Ajzen & Fishbein, 1980) as a framework for investigating factors that influence caregiver decision to continue/discontinue medicating their children with ADHD. Thirty-four caregiver-child dyads filled out a series of self-report questionnaires. A regression model, designed to predict caregiver intention to (dis)continue the child's ADHD medication, was built using the three basic components of the theory of planned behaviour (attitudes, perceived behavioural control, and subjective norms) as well as a variable capturing satisfaction with current medication regime. The final model explained more than 43% of the variance in that intention. The results of this study could be used to inform health-care providers about factors influencing the caregiver decision to initiate and to continue medicating children with ADHD.

Caregivers of children with attention-deficit/hyperactivity disorder (ADHD) undergo a taxing process regarding the decision to initiate and continue pharmacological treatment of their child's disorder. A possible reason for the challenging nature of this decision is the lack of consensus regarding the effects and outcomes of ADHD medication. Stimulant medication is the most widely used treatment for ADHD, and has been proven to be most effective in treating the core symptoms of this disorder (Adelman, 2001; Hall & Gushee, 2002). Yet, because of side effects, societal stigma, and other idiosyncratic reasons, many caregivers make the decision to discontinue using medication to treat their child's ADHD.

Considering that this is a pivotal decision, it is surprising that no studies have investigated the factors that lead caregivers to continue or discontinue their child's ADHD medication use. Consequently, this study aims to examine factors that lead caregivers of children with ADHD to make the decision to (dis)continue stimulant medication use. We used the theory of planned behaviour (TPB) to explore those factors influencing the behavioural intention regarding the decision.

ADHD: Clinical characteristics

ADHD is the most commonly diagnosed childhood neurological-behavioural condition. It is estimated that approximately 3-7% of all school-age children in Europe and the United States are diagnosed with ADHD (American Psychiatric Association [APA], 2000), and that approximately 8-10% of the South African population meet diagnostic criteria for the disorder (ADHASA, 2010).

ADHD is characterised by unrelenting inattention and/or hyperactive behaviours and extreme impulsivity. *Inattentiveness* is understood as difficulty in sustaining attention, and occurs especially if the task needing attention appears to be uninteresting (Frankenberger & Cannon, 1999). *Hyperactive-impulsive behaviour* includes impatience and excessive action and speech (Snyder, Maruff, Pietrzak, Cromer, & Snyder, 2008). These inattentive, hyperactive, and impulsive behaviours are much more excessive in people with ADHD than in individuals of a comparable developmental level. For a diagnosis to be made, symptoms of the disorder must be present before the age of 7 years and they must cause interference in two or more of the individuals' social environments (e.g., work, home, and/or school; APA, 2000).

An individual with ADHD can either be diagnosed with Attention-Deficit/Hyperactivity Disorder Predominantly Inattentive Type (ADHD-PI), Attention-Deficit/Hyperactivity Disorder Predominantly Hyperactive-Impulsive Type (ADHD-HI), or

Attention-Deficit/Hyperactivity Disorder Combined Type (ADHD-CT). Children diagnosed with ADHD-PI have difficulty maintaining focus on a task for a long period of time and are easily distracted and often forgetful. Children with ADHD-HI might have difficulty controlling their behaviour in the classroom environment, and may shout out answers and fidget constantly. Children who display symptoms of both of the above are diagnosed with ADHD-CT; these children experience difficulties related to ADHD-PI as well as those related to ADHD-HI (Snyder et al., 2008). Appendix A presents a complete description of the diagnostic criteria for ADHD, as laid out in the text revision of the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; APA, 2000).

Children with ADHD are often described as difficult from birth and as challenging for their caregivers, and they often have inconsistent and irregular sleep patterns. Many caregivers complain that their child with ADHD skipped the walking period of development, and instead progressed from crawling to running (Frankenberger & Cannon, 1999). At school, the inattentive and hyperactive tendencies of the ADHD child can have a dramatic impact on classroom work and on academic performance, and can also affect the concentration of other learners (APA, 2000). Thus, ADHD can be strenuous not only for the child, but also for others in contact with the child.

ADHD: Treatment

Treatment for ADHD can take the form of psychosocial interventions (e.g., caregiver training and counselling), behaviour modification, dietary supplements, pharmacological treatment, or some combination of the four (Adesman, 2001; Jackson & Peters, 2008). Pharmacological interventions are, however, the most widely used. Of the pharmacological interventions available, stimulant medications are used most often (Alto & Frankenberger, 1995; McNeal, Roberts, & Barone, 2000; Pelham et al., 2005). The most popular stimulants prescribed for ADHD treatment are methylphenidate (Ritalin), dextroamphetamine (Dexedrine), and pemoline (Cylert; Frankenberger & Cannon, 1999).

Ritalin is the most studied and most frequently used stimulant medication. It reduces motor activity more effectively than Dexedrine, which is longer-lasting and less expensive (Hall & Gushee, 2002). Cylert is also effective in treating ADHD, and is often a popular option for parents and children because it only has to be taken once a day, whereas most other stimulants have to be taken more regularly (Adesman, 2001). A fairly recent form of methylphenidate, Concerta, is now available. This stimulant is also taken once a day.

When administered correctly, stimulant medications have proven to be effective in the management of ADHD symptoms (Adelman, 2001; Hall & Gushee, 2002). They have been shown to reduce the core symptoms of ADHD (hyperactivity, impulsivity, and inattentiveness) dramatically. Stimulant medications can also decrease physical and verbal aggression, and improve social interaction with peers, family, and teachers. Children on medication improve academically, as medication helps them concentrate and stay focused.

Frankenberger and Cannon (1999) suggest that there are two primary reasons for prescribing stimulant medication to children with ADHD. Firstly, one might prescribe these medications to assist children in learning and to improve their academic achievement by reducing their impulsivity and increasing their attention to academic tasks. Secondly, one might prescribe these medications to create an environment that fosters classroom learning by alleviating the disruption caused by hyperactive and impulsive children.

ADHD children experience cognitive difficulties that are distinct from their difficulties with behavioural functioning in the academic environment. For instance, Snyder et al. (2008) found that the executive functioning of children with ADHD improved when they were on stimulant medication. They also concluded that working memory, trial-and-error learning, and inhibitory control improve as a result of stimulant treatment. When the medication wears off or is discontinued, some of the neuropsychological gains, such as the ability to pay attention to detail and the ability to plan and organise, are sustained (Semrud-Clikeman, Pliszka, & Liotti, 2008).

Although stimulant medications do improve behavioural difficulties, this improvement is neither permanent nor long-lasting: Once the medication starts to wear off, the behavioural problems appear once again. These behavioural difficulties are strong motivators for the caregiver decision to initiate and maintain ADHD medication.

Caregiver views regarding ADHD medication and the use thereof are important, as caregivers ultimately decide whether to continue or discontinue treatment (Stroh et al., 2008). Given that stimulant medication is the most commonly used treatment for ADHD, and that the effects thereof are beneficial for the overall functioning of the child diagnosed with this disorder, one is left wondering why caregivers who initiate medication might discontinue the treatment. Yet studies show that even after a 1-year period on the medication, caregivers often discontinue their child's ADHD medication (Marcus, Wan, Kemner, & Olfson, 2005). Reasons for this decision may include side-effects (e.g., decreased appetite, dizziness, stomach-aches, motor tics, insomnia, headaches, and irritability) associated with the medication (McNeal et al., 2000). Although contradictory opinions exist as to whether

stimulant medications impede physical growth, parents might discontinue the medication because of fears around such stunting (Adesman, 2001; Hall & Gushee, 2002). There are also caregiver concerns about dependency and abuse of stimulant drugs (Kollins, 2007; Stroh, Frankenberger, Cornell-Swanson, Wood, & Pahl, 2008). Furthermore, it appears that mothers worry that their children's personalities may change and that they may become emotionally flat when medicated (Jackson & Peters, 2008; Neophytou & Webber, 2005). It has been said that children on ADHD medication appear 'zombie-like' (dosReis & Myers, 2008).

Regardless of these perceived and/or actual negative effects, many caregivers still choose to medicate their ADHD child. Studies reveal that scepticism and conflicting opinions of referent groups (e.g., friends, family members, teachers, health professionals; Jackson & Peters, 2008) may cause caregivers to wonder whether medication will actually benefit their child with ADHD. However, once the decision to use medication as the primary treatment intervention is made and adhered to, caregivers are generally happy with its effects (Klassen, Miller, Raina, Lee, & Olsen, 1999).

From an empirical psychological perspective, however, "little is known about how caregiver views [regarding ADHD medication] guide their treatment decisions and influence continuity of treatment" (dosReis et al., 2009, p. 378). Consequently, we aim to investigate factors that lead caregivers to terminate or maintain treating their ADHD children with stimulant medication. More specifically, we aim to show how the theory of planned behaviour (Ajzen & Fishbein, 1980) can be used as a prediction tool to identify whether particular caregivers are more likely to decide to continue or discontinue stimulant medication treatment for their ADHD child.

Theory of Planned Behaviour

Ajzen and Fishbein's TPB is based on the major premise that people are rational and make logical sense of the information available to them. According to the TPB, certain behaviours are a direct result of behavioural intention. Behavioural intention can be traced to three predictive components: attitudes towards the action, subjective norms regarding the action, and perceived behavioural control over the action.

Attitudes towards the action describe the individual's beliefs about the likely outcomes of the behaviour, and his/her positive and negative evaluations of these outcomes. *Subjective norms* refer to what the individual believes other people think of the behaviour, and include perceptions of social pressure to comply with these norms. *Perceived behavioural control* refers to whether or not the individual believes that he/she is capable of

performing the behaviour. Thus, this component does not measure whether or not the individual is actually in control of the behaviour, but instead measures the individual's subjective belief regarding his/her control over the behaviour.

Combining these three components makes up behavioural intention. The behavioural intention, in turn, indicates how much effort the individual will go through to perform the behaviour. The greater the intention to perform the behaviour, the more likely the individual is to carry out the behaviour. Otherwise stated, the strength of the behavioural intention predicts the likelihood of the individual engaging in the behaviour (Ajzen, 1991; Ajzen & Fishbein, 1980; Kos, 2004).

The TPB is a reliable model to predict and explain behaviour, as it has been used in many studies and has extensive empirical evidence to support it (see, e.g., Ajzen 1991; Anderson & Lavalley, 2008; Herbert, Urmie, Newland, & Farris, 2006; Kos, 2004). The TPB can be applied to the decision caregivers of children with ADHD make with regard to medication use; specifically, the theory can be used to predict and explain whether or not caregivers will continue their child's stimulant medication use.

Attitudes toward ADHD medication use affects the caregiver's intention to continue medication (Zametkin & Ernst, 1999). The child's attitude towards his/her medication is also an important factor to consider in the caregiver's intention, as the child's attitude may be an important variable in the treatment outcome (Efron, Jarman, & Barker, 1998). The attitudes experienced by the caregivers of the child diagnosed with ADHD are positively correlated to what the child feels and thinks about his/her treatment. But, caregivers often see more medication benefits than their children do, and children see more drawbacks to taking the medication (Harpur et al., 2008; Stroh et al., 2008). The important relationship between caregiver and child attitudes, as well as the possible lasting influence caregivers have on their child's health beliefs, behaviours, and attitudes (McNeal et al., 2000), motivated us to combine caregiver and child attitudes towards ADHD medication into the attitude component of our TPB model. This attitude component can therefore be referred to as the family attitude.

Subjective norms regarding ADHD medication use are the perceived beliefs caregivers have concerning whether significant others think medication should be used to treat children with ADHD. Caregivers who decide to medicate their ADHD child may feel pressurised to continue or discontinue medicating because of differing opinions of important referent individuals or groups. For instance, caregivers often feel pressurised by teachers and other professionals (e.g., psychologists, psychiatrists, and general practitioners) to continue medicating their child. These referent groups often have contradictory opinions to the media

and the community, who tend to view stimulant medication negatively. The media also play a large role in the medication decision-making process, as they often portray children with ADHD as badly behaved and unmannered, as opposed to having a legitimate medical condition (Brinkman et al., 2009; Jackson & Peters, 2008). This portrayal might lead some individuals to think they are bad caregivers with disobedient children, and to consider the decision to medicate undeserved.

Caregivers do not take the decision to continue medicating their children with ADHD lightly, as they often feel they have to defend themselves to family and friends who might favour discontinuation (Jackson & Peters, 2008). As noted above, caregivers who do prefer medication as a treatment plan often have a positive attitude towards medication due to the calming affect it has on their hyperactive child (Stroh et al., 2008). However, these calming affects are frequently seen by other caregivers as a means to make the hyperactive child a 'zombie' rather than to treat the behavioural problem properly (dosReis & Myers, 2008).

Perceived behavioural control regarding ADHD medication use is the belief caregivers have concerning their capability to decide whether or not to continue medicating their ADHD child. Under ordinary circumstances, caregivers make the final decision regarding ADHD treatment. In terms of this component of the TPB, they therefore perceive that they hold all the control over this important decision. As the TPB states, there is a possible link between perceived behavioural control and the execution of the behaviour. In order for this link to exist, however, the perceived behavioural control must parallel the actual behavioural control. The latter depends on non-motivational factors, such as opportunities and resources (Ajzen, 1991). Examples of the opportunities and resources that may affect caregivers of children with ADHD and their decision to continue medicating their children are money, time, and the cooperation of the child.

As can be seen, the combination of attitudes, subjective norms, and perceived behavioural control contributes to the caregiver's behavioural intention concerning whether to continue medicating the ADHD child. Moreover, in this study, a satisfaction of medication component has been added to the TPB model in order to assist in the prediction of caregiver intention to continue medicating their child diagnosed with ADHD.

Satisfaction with stimulant medication is associated with the continued use of that medication. Satisfaction and attitude are highly positively correlated (dosReis et al., 2003), and thus, if caregivers and children are satisfied with the effects of ADHD medication, their attitudes towards this stimulant treatment will also be positive. Moreover, if both child and caregiver are satisfied with the ADHD medication and its treatment of the ADHD symptoms,

the medication is likely to be continued. If both the child with ADHD and his/her caregiver perceive the disadvantages of the treatment (e.g., negative side effects of the medication) as outweighing the advantages, they are likely to cease the treatment plan regardless of the effects on the core symptoms of the disorder (Harpur, Thompson, Daley, Abikoff, & Sonuga-Barke, 2008).

To our knowledge, few studies have focused on the decision caregivers make to continue or discontinue medicating their child with ADHD. No studies have used the theory of planned behaviour in order to predict caregiver intention to continue ADHD medication. Consequently, we explore this decision in terms of the various factors comprising the theory of planned behaviour, along with a closely related component, satisfaction with medication. We also examine the relationship between child and caregiver attitude towards ADHD medication, as few studies actually consider the child's attitude towards his/her medication. The results of this study could be used to inform health-care professionals about what factors are important to caregivers when making decisions regarding the continuation of ADHD medication.

Methods

Research Design and Setting

This relational, cross-sectional research study used quantitative methods, and featured semi-structured interviews and a series of self-report questionnaires.

The venue for our interview session was most often the participant's residence, although some participants preferred to meet at a research laboratory in the Department of Psychology at the University of Cape Town. Our goal was to create the most comfortable and relaxed environment possible, so as to facilitate the ease of the meeting. This was especially relevant for the child, who may have felt uncomfortable in an unknown environment speaking to unknown people.

Participants

The sample ($N = 34$) included children previously diagnosed with ADHD by a recognised medical or mental health professional, ranging from ages 7 to 18 years, as well as their primary caregiver (typically mother, father, or guardian). Because of resource constraints regarding measurement translation and the availability of interpreters, we recruited only caregivers and children who were fluent in either English or Afrikaans. We placed no restrictions on the sample in terms of sex, race, religion, social class, and

socioeconomic status, however. Children with co-morbid psychotic disorders were excluded from participation, as they are in almost all studies of this kind. Children also needed to be on ADHD medication to be included in this study.

Table 1 presents a complete demographic description of the sample. As the table shows, the sample of 34 caregiver-child dyads was relatively homogenous in terms of demographic characteristics. For example, most participants were White, English-speaking, suburban-dwelling individuals of at least medium SES.

The recruitment process involved the distribution of a poster (see Appendix B) designed specifically to recruit participants for this study. We contacted private remedial school principals to obtain permission to (a) put up posters on their school notice boards, and (b) circulate flyers of this poster to the caregivers of the school pupils. We also used the Internet to recruit participants: We advertised our poster on the Attention Deficit Hyperactivity Support Group of Southern Africa (ADHASA) website, as well as on the Living ADDventure (LADD) website. The online social networking site, Facebook, was also used to promote our study. Furthermore, various ADHD support groups advertised this study and provided a platform for interested participants to gather information.

Materials

Child participants completed an assent form (Appendix C), the Children's Perception of Hyperactivity Medication (CPHM) questionnaire, and the Mini International Neuropsychiatric Interview for Children and Adolescents (M.I.N.I. Kid). Caregivers completed an informed consent document (Appendix D), a demographic questionnaire (Appendix E), the Attitudes, Satisfaction, Knowledge & Medication Experiences with ADHD Medicine Treatment (ASK-ME) survey, the Caregiver's Perception of Hyperactivity Medication (PPHM) questionnaire, the Subjective Norms scale (Appendix F), as well as the Perceived Behavioural Control and Behavioural Intention (PBCBI; Appendix G) scale. Details of each of these measures are provided below.

Demographic questionnaire. This instrument was used to capture data involving information about the participants' lives, including aspects such as age, sex, race, religious orientation, home language, and socioeconomic status.

Child measures. The *Mini International Neuropsychiatric Interview for Children and Adolescents (M.I.N.I. Kid; English version 5/6; Sheehan, Shytle, & Milo, 1998)* was used as a diagnostic tool to assess the mental health of the ADHD children, and especially to re-affirm the ADHD diagnosis. It also served the purpose of identifying whether these participants

displayed co-morbid psychotic symptomatology, which was essential for determining whether or not the child was eligible for participation in this study. Recent research has confirmed the M.I.N.I. Kid as a reliable and valid psychiatric diagnostic tool for children and adolescents (Sheehan et al., 2010).

Table 1
Demographic Characteristics for the Sample of Caregiver-Child Dyads (N = 34)

Variable	
Age (years)	
Caregiver range	33-51
Caregiver mean (SD)	42.18 (5.34)
Child range	7-18
Child mean (SD)	10.50 (2.73)
Sex (males:females)	
Caregiver	2:32
Child	25:9
Race	
White:Coloured	28:6
Religion	
Christian	30
Islam	1
Jewish	2
Atheist	1
Language	
English:Afrikaans	27:7
Caregiver marital status	
Single:Married:Separated:Divorced	2:20:3:9
Neighbourhood	
Suburban:Urban:Rural	25:5:4
Family income bracket (per annum)	
R0-R35000	3
R36000-R75000	0
R76000-R125000	4
R126000-R175000	3
R176000-R225000	3
R226000-R275000	4
R276000-R325000	1
R326000-R375000	2
R376000-R425000	2
R426000-R475000	3
R476000-R525000	0
> R526000	9

The *Children's Perception of Hyperactivity Medication (CPHM; McNeal et al., 2000)* questionnaire consists of 20 items which are answered on a Likert-type scale (1 = *definitely not*, and 5 = *definitely yes*). In this questionnaire, six items focus specifically on concern with

illness, another six relate to the perceived benefit of continuing medication, and positive changes of behaviour as a result of utilizing ADHD medication. A further six questions assess the perceived cost and barriers of taking medication, such as aspects relating to the child's peers and schooling environment. The final two items ask about how children with ADHD perceive the severity of their disorder. Previous ADHD research (McNeal et al., 2000) employed this questionnaire to explore the child's attitude towards his/her ADHD medication. This questionnaire was beneficial to use as it contributed to the measurement of one of the study's core components: The family attitude toward medication use and possible (dis)continuation.

Caregiver measures. The *Attitudes, Satisfaction, Knowledge & Medication Experiences with ADHD Medicine Treatment (ASK-ME; dosReis, 1999)* survey is a self-administered questionnaire consisting of 47 items. It consists of five sections, one being demographic in nature. The section that was used for this study consists of eight items and assesses the caregiver's satisfaction with ADHD medication in terms of the academic, behavioural, and social improvement in the performance of the child with ADHD. This measurement has been used in a number of ADHD studies (e.g., dosReis et al., 2003), and the internal consistency measures of reliability for satisfaction have been high.

The *Parent's Perception of Hyperactivity Medication (PPHM; McNeal et al., 2000)* questionnaire encompasses 20 items focusing on illness concern, perceived benefits of ADHD medication, and the perceived cost and barriers of taking the medication. There are also two items that specifically assess the level of perceived severity of the disorder. This caregiver questionnaire parallels the child questionnaire (CPHM); however, it is made clear that the caregiver is the subject of focus. For example, an item on the child questionnaire might state, "My behaviour is better when I take my medication," whereas the corresponding item on the caregiver questionnaire might state, "My child's behaviour is better when he/she takes his/her medication." Previous ADHD research (McNeal et al., 2000) employed this questionnaire to explore the caregiver's attitude towards ADHD medication. This questionnaire is important to comprehending what caregiver attitudes are towards their children's use of ADHD medication, and it also formed part of the family attitude component of our model.

The *Subjective Norms* scale was designed specifically for this study to measure what caregivers believe other important referent individuals or groups think about their choice to continue medicating their ADHD child. This scale mentions 18 important referent individuals or groups (e.g., grandparents, school, media, community). Caregivers were required to tick

the most appropriate response option from the following four choices: *not available*, *unsure*, *disapprove*, and *approve*.

The *Perceived Behavioural Control and Behavioural Intention (PBCBI)* scale measures the perceived behavioural control and behavioural intention components of the TPB. This scale was designed specifically for this study to measure factors associated with the TPB, namely perceived behavioural control and behavioural intention.

Procedure

Caregivers interested in participating contacted the researchers via telephone and/or email. We corresponded with them to provide more information about the study, and if they maintained their interest in participating, specific dates, times, and venues for the assessment session were arranged.

Two researchers were present at every assessment. Each researcher had been trained in a standardized way in order to ensure consistency throughout the data collection. One researcher administered the assessment instruments to the child, while the other administered the instruments to the caregiver.

On arrival at the interview session, the researchers introduced themselves and their research to both the caregiver and the child. At this point, any uncertainties were clarified, and a setting of openness and ease was established.

The caregiver was asked to read and sign the informed consent document; if necessary, the researcher read the form to the participant. Thereafter, the caregiver completed the remaining caregiver questionnaires, with the assistance of the researcher when required. During this process, the researcher was available to answer any questions the caregiver might have had concerning the questionnaires or the research.

The child read the assent form if he/she was capable of doing so; otherwise, the researcher read the form to him/her. The child was then asked to write his/her name on the assent form, thus giving the researchers permission to go forward with the assessment. The researcher then administered the questionnaires to the child, in such a way that the language use was appropriate to the developmental level and age of the participant.

Once the assessment session was complete, both caregiver and child were given the opportunity to voice any concerns or opinions about the research and about the process of assessment. This debriefing/feedback session also served as a chance for the open expression of feelings concerning the disorder and the effects it had had on the family's life.

Approximately 1 week after participation, the caregiver received detailed written

feedback about the information gathered during the assessment. This feedback letter included details concerning the caregiver's and child's perceptions about the ADHD medication. Furthermore, the feedback letter provided recommendations as to how caregivers can obtain more information about ADHD and its treatment.

Statistical Analysis

The measures described above were used to derive the three components of the TPB (attitudes, subjective norms, and perceived behavioural control), the caregiver's satisfaction with current use of the medication, as well as the intention of caregivers to continue their child's ADHD medication. All the items on the CPHM and PPHM questionnaires contributed to the attitude component of the TPB. The whole Subjective Norms scale measured the subjective norm component of the TPB. The PBCBI scale was used to measure the caregiver's perceived behavioural control over, and their behavioural intention towards, the decision to continue medicating their ADHD child. The measure of satisfaction with current medication use was derived from ASK-ME survey items 32 to 39.

Data were analysed using the PASW statistical software package, version 18 (PASW Statistics, 2009). The threshold for statistical significance was set at .05. Data analysis proceeded over six stages.

Firstly, detailed descriptive statistics were compiled in order for us to gain greater familiarity with the patterns of association between different variables, and to ascertain whether the data met the assumptions underlying parametric tests.

Secondly, we made sure that the items on the PPHM and the CPHM were all scored in the same direction, so that higher scores (on the Likert-type scales) reflected a more positive attitude. Twelve questions (2, 3, 9, 10, 11, 12 from the PPHM, and 2, 3, 9, 10, 11, 12 from the CPHM) were reverse coded. Cronbach's alpha (α) correlation coefficient was then calculated for the items on the two questionnaires together in order to test whether they could be combined reliably into one variable, called family attitude.

Thirdly, descriptive data for the factors comprising the final regression model were examined, specifically to inspect the distribution patterns and trends between the factors. The independent variables (predictors) used in the model were family attitude, subjective norms, perceived behavioural control, and satisfaction. The dependent (outcome) variable was the caregiver's behavioural intention, which was the decision to (dis)continue the child's ADHD medication.

Fourthly, we examined the correlations between all the variables included in the regression model. This step was taken in order to establish whether the factors were intercorrelated.

Fifthly, we ran a hierarchical regression in order to build the best-fitting model to account for all or most of the systematic variance in behavioural intention. All the assumptions for multiple regression analysis were successfully met. There was no perfect multi-collinearity between the independent variables, the distribution of data was homoscedastic and linear, all the residuals in the model were independent, random, normally distributed variables, and each value of the outcome variable emerged from a separate entity, thus making it independent.

Finally, in a separate analysis, we focused on the overall relationship between the caregiver's and child's attitude towards ADHD medication, as well as the relationship between their attitudes towards illness concern, perceived medication benefits, perceived severity of ADHD, and perceived cost and barriers to taking medication. These relationships were based on the caregiver's and child's responses to the PPHM and CPHM respectively, and were analysed using McNemar's test of disagreement. All the assumptions underlying this test were met.

Results

Statistics Relating to the Regression Model

The following section describes the variables contained in the final regression model, as well as how these were derived from the various measures used during data collection.

Descriptive statistics for model variables. Table 2 presents descriptive statistics for all of the variables used in the regression model. All individual items on the questionnaires were measured on a Likert-type scale (1 = *strongly disagree*, and 5 = *strongly agree*) except for those items on the Subjective Norms scale, which was measured on a scale of -1 to 1, reflecting the perception of whether significant others approve/disapprove of medication continuation. Higher scores in the Table therefore signify more positive attitudes toward medication use, a greater approval by significant others and groups surrounding medication use, more perceived behavioural control over continued medication use, greater satisfaction with current medication use, and stronger intention to continue medication use.

Table 2
Descriptive Statistics for Variables Used in the Current Model (N = 34)

Construct	Items	Range of Scores	Mean (SD)
Attitude	38	86-164	130.26 (13.27)
Subjective norms	18	1-14	7.50 (2.92)
Perceived behavioural control	1	2-5	4.38 (1.10)
Satisfaction	8	2-32	21.29 (6.17)
Intention	1	1-5	4.44 (0.82)

As the Table shows, there was considerable variability in the factors assessing intention to continue medication. There was also some variability in the intention to continue medication use.

Derivation of variables. With regard to the way in which the attitude variable was derived, several measures used during data collection measured the attitudes of the caregiver and the child towards ADHD medication. Moreover, we wanted to add knowledge to the attitude component of the TPB, as in general, knowledge and attitude are correlated (Olson, Goffin, & Haynes, 2007). However, the Cronbach's α for this combination of measurements was unsatisfactory, and, in general, it was challenging to determine which combination of measures should be incorporated into the final model as an accurate measure of attitude toward continued medication use. A series of internal consistency tests, using Cronbach's α , demonstrated that the combined PPHM and CPHM scales had an internal consistency reliability of .725, which is higher than the conventional benchmark (.70) for adequate internal consistency (Field, 2009). We thus decided that the attitude component of our TPB model would comprise the combination of these measures, and would be most properly designated as 'family attitude'. The CPHM and PPHM were combined by summing the scores of each corresponding item, so that each item would now be worth a maximum of 10 points, instead of 5. It is that family attitude variable that is described in Table 2.

We decided to only use one question from the PBCBI, rather than all six questions, to measure the intention to continue medication use. We made that decision because the question directly states, "I intend to maintain my child's ADHD medication." The item stating "I intend to discontinue my child's ADHD medication" was used as a fidelity check for the chosen intention question; the two items correlated at $r = -.701, p < .001$.

Correlation between variables. Table 3 shows the correlation matrix for all the variables in our model. As can be seen, there were strong and statistically significant relationships between many of the variables. Scores on the measures of subjective norms and perceived behavioural control were not strongly correlated with scores on any of the other

variables. The strongest correlations were between the measures of family attitude and intention, and between family attitude and satisfaction.

Table 3
Correlation Matrix for all Variables in the Model

	1	2	3	4	5
1. Intention	1.00				
2. PBC	$r = .310$ $p = .075$	1.00			
3. Subjective norms	-.170 .335	.099 .577	1.00		
4. Satisfaction	.523 .002*	.054 .760	.071 .691	1.00	
5. Family attitude	.563 < .001**	.308 .076	.224 .202	.533 < .001**	1.00

Note. PBC = perceived behavioural control.

* $p < .01$; ** $p < .001$

Hierarchical regression analysis. This section is pivotal for our study, as it involves building a model to predict caregiver's intention to continue their child's ADHD medication.

Table 4 provides a summary of our hierarchical regression analysis. The standard TPB components (attitude, subjective norms, and perceived behavioural control) were used as a first model-building step in order to predict caregiver's intention to continue medicating their child with ADHD. The overall model for this step was significant, $F(3, 30) = 7.64, p = .001$, and consequently, we can see that the standard TPB model significantly predicted this intention. Attitude was a significant predictor of intention, $t = 3.96, p < .001$, and it had the greatest influence on the model. Subjective norms significantly influenced intention, but in the opposite direction from what might have been expected, $t = -2.25, p = .032$. Perceived behavioural control did not play a significant role in predicting the intention, $t = 1.11, p = .275$. Even though 70.6% of the caregivers believed that they had full control over the decision to continue medicating their child, this belief had no significant impact on their actual intention. Overall, this first step of the model explained 37.6% of the variance in the caregiver's intention to continue medicating their child with ADHD.

In step 2 of the analysis, a fourth predictor variable, satisfaction, was added to the model. The addition of more variables to the standard TPB model in order to increase predictive power has precedent in the literature. For instance, Beck and Ajzen (1991), in a

study predicting ethical behaviour in college students, used a measure of moral obligation as well as the conventional TPB components. As Table 4 shows, at step 2 attitude still had the greatest predictive influence, $t = 2.34$, $p = .024$. The newly-added variable, satisfaction, had the second greatest predictive influence, $t = 2.05$, $p = .049$. Moreover, satisfaction added predictive power to the model by explaining a further 7.2% of the variance in intention to continue medication.

At step 2, subjective norms still had a significant influence on the model, and that influence remained in the opposite direction of what might be predicted, $t = -2.25$, $p = .032$. Perceived behavioural control also remained an insignificant contributor to the model, $t = 1.44$, $p = .161$.

Overall, the final model was statistically significant, $F(4, 29) = 7.40$, $p < .001$, and explained 43.7% of the variance in caregiver intention to continue medicating the child with ADHD. The regression equation for the model is: Caregiver's intention to continue medicating their child with ADHD = $0.294 + (0.025)\text{attitude} + (-0.085)\text{subjective norms} + (0.149)\text{perceived behavioural control} + (0.0434)\text{satisfaction}$. Although each of the three standard TPB components did not make an independent, statistically significant contribution to our attempt to model intention to continue medication, this is not unusual in the TPB literature. As Ajzen (1991, pp. 188) notes, "The relative importance of attitude, subjective norm, and perceived behavioural control in the prediction of intention is expected to vary across behaviours and situations."

Table 4
Hierarchical Regression Analysis: Predicting Intention to (Dis)Continue ADHD Medication

	<i>B</i>	<i>SE B</i>	<i>B</i>
Step 1			
Constant	-0.14	1.12	
Attitude	0.04	0.01	.59*
Subjective norms	-0.09	0.04	-.32*
Perceived behavioural control	0.12	0.11	.16
Step 2			
Constant	0.29	1.09	
Attitude	0.03	0.01	.40*
Subjective norms	-0.09	0.04	-.30*
Perceived behavioural control	0.15	0.10	.20
Satisfaction	0.04	0.02	.32*

Note. $R^2 = .43$ for Step 1; R^2 change = .072 for Step 2.

* $p < .05$.

Comparison between Caregiver and Child Attitude towards ADHD Medication

As the family attitude component of the TPB had the greatest influence on the final model, and this component consisted of the combined caregiver and child attitude towards ADHD medication, we decided to explore the agreement/disagreement between the attitudes of the caregiver and child. Using the PPHM and CPHM data, we compared the overall attitudes of children and caregivers, as well as their attitudes in terms of the four subscales of these measures (illness concern, perceived medication benefits, perceived severity of ADHD, and perceived cost and barriers of taking ADHD medication).

Overall caregiver and child attitudes. We converted the Likert-type scale present in the PPHM and CPHM (1 = *definitely not*, and 5 = *definitely yes*) to a dichotomous variable representing positive or negative attitudes towards ADHD medication. Together, *definitely not* (1) and *probably not* (2) were collapsed into one category (a negative attitude towards ADHD medication). *Maybe* (3), *probably yes* (4), and *definitely yes* (5) were collapsed into another category (a positive attitude towards ADHD medication). We then used the McNemar's test of disagreement to assess the degree of difference between the child's and caregiver's perceptions towards ADHD medication. The analysis detected statistically significant differences between the child and caregiver reports, $\chi^2(1) = 21.01, p < .001$. This finding suggests that the attitudes of the child and caregiver differed from one another. Figure 1 is a visual representation of the caregiver's and child's responses to the PPHM and CPHM.

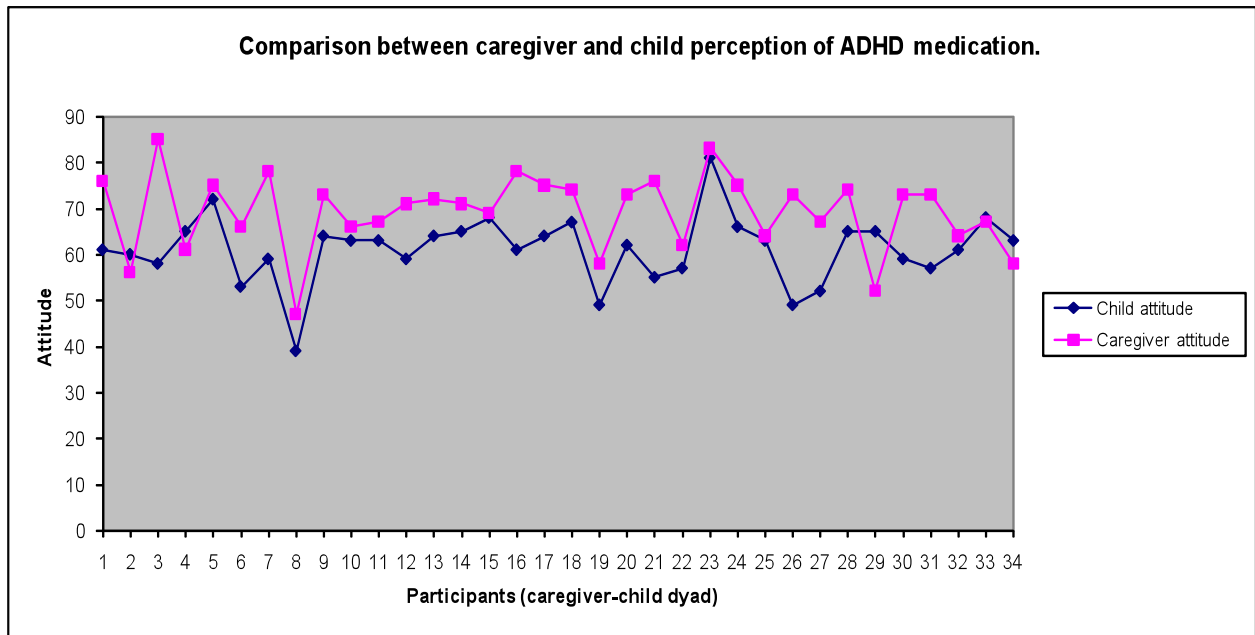


Figure 1. Line graph representing the caregiver's and child's responses to the PPHM and CPHM questionnaires. The x-axis represents each caregiver-child dyad ($N = 34$). The y-axis represents the total score of each participant on the questionnaire. A high score indicates a positive attitude towards ADHD medication. When points for each caregiver-child dyad are close to one another, that represents agreement; when they are far apart, that represents disagreement.

Figure 1 reveals that the caregiver and child attitudes are different from one another. Also, the caregivers had a more positive attitude towards ADHD medication than their children did, which is illustrated by the fact that the caregiver line on the graph is higher than that of the child. The mean for the overall caregiver attitude is 69.18 ($SD = 8.43$) and the mean for the overall child attitude is 61.09 ($SD = 7.38$). However, the response of the caregiver and child often paralleled one another in terms of response direction. Dyads 5 to 9 demonstrates this response direction clearly. Also interesting to note is that dyad 8 were the only participants who stated a clear intention to discontinue medication use, and, accordingly, the attitudes of the caregiver and child towards medication were very low. Another point to note is that the caregiver and child attitudes of dyads 15, 23, and 33 were very similar, whereas the caregiver and child attitudes of dyad 3, 7, and 26 were quite different. It would be interesting to investigate the reasons for these similarities and discrepancies between the caregiver and child, but such investigation is beyond the scope of the current study.

Subscales of the CPHM and PPHM. Based on the descriptive statistics displayed in Table 5, we ran four separate McNemar tests of disagreement to assess the degree of difference between the child's and caregiver's attitudes on the subscales measuring illness

concern, perceived medication benefits, perceived severity of ADHD, and perceived cost and barriers of taking medication. As Table 6 shows, illness concern was the only subscale on which children and caregivers disagreed significantly. Data for the rest of the subscales were not statistically significant, indicating that the children's and caregivers' responses on these subscales were consistent with one another.

Table 5
Descriptive Statistics: Responses to CPHM and PPHM (N = 34)

Subscale	Caregiver Mean (SD)	Child Mean (SD)
Illness concern	13.09 (3.16)	10.94 (2.70)
Perceived medication benefits	12.91 (2.30)	11.88 (1.87)
Perceived severity	3.32 (1.07)	3.09 (1.36)
Perceived cost and barriers	9.12 (2.03)	9.53 (2.43)

Table 6
McNemar Test: Caregiver-Child Disagreement on the CPHM and PPHM (N = 34)

Subscales	χ^2	<i>P</i>	Odds ratio	95% CI
Illness concern	14.754	< .001*	3.067	1.681 - 5.914
Perceived medication benefits	0.000	1.000	1.167	0.336 - 4.202
Perceived severity	1.125	.288	3.000	0.536 - 30.393
Perceived cost and barriers	0.281	.595	0.778	0.358 - 1.655

Note. χ^2 value is based on 1 degree of freedom; *p*-values are two-tailed; 95% CI = 95% confidence interval.

****p* < .001

Discussion

This study sought to use the theory of planned behaviour to investigate the factors influencing caregiver decision to continue or discontinue medicating their child diagnosed with ADHD. It is the first study to examine these factors using the TPB. Specifically, attitude, subjective norms, and perceived behavioural control were used to build a model to predict caregiver intention. We added the important predictor variable of satisfaction with current ADHD medication to our final model. We also compared the caregiver's and child's attitudes towards medication, an examination of which is also lacking in the current ADHD literature.

Predicting ADHD Medication Continuation

The attitude component of our model was comprised of a combination of the caregiver's and child's attitudes towards ADHD medication. Thus, we considered this

component to be more accurately termed ‘family attitude toward ADHD medication’. This component of the model was, as we expected, a crucial predictor of the intention to continue ADHD medication; in fact, it had the strongest influence on the model. Specifically, a positive family attitude increased the intention to continue medication, whereas a negative family attitude decreased the behavioural intention. Therefore, when determining whether a caregiver is likely to continue medication, examining the attitude of both the child and the caregiver toward medication is a critical factor.

The subjective norms component of the model had an effect in an unexpected direction: The data suggested that, as scores on the measure of subjective norms increased, the likelihood of continuing medication decreased. Because higher scores on that measure indicated more perceived approval from others to continue medication, and lower scores indicated more perceived disapproval to continue medication, this effect is in the opposite direction from what one might predict. This finding is interesting and requires some interpretation.

A possible interpretation of the observed pattern of data regarding subjective norms is derived from some post-hoc linear regression analyses we conducted. Specifically, a regression analysis with subjective norms as the only predictor of intention produced a model that was not statistically significant, $F(1, 32) = 0.96, p = .335$. In contrast, when the significant predictors within our final regression model (family attitude and satisfaction) were used as separate predictors of intention in separate regression analyses, both produced statistically significant models, $F(1, 32) = 14.86, p = .001$ and $F(1, 32) = 12.02, p = .002$, respectively. This pattern of data leads us to assume that subjective norms do not, in actual fact, play a role in predicting intention, despite what the final model might indicate.

An alternative interpretation of the observed pattern of data regarding subjective norms is that the instrument used to measure subjective norms was psychometrically unsound. We developed this measure for the specific purposes of this study, and have no data as to its test-retest reliability or construct validity. Gathering such data would be an important step in improving the measure. Another way to improve the measure would be to include questions dealing with the subjective norms surrounding *discontinuing* ADHD medication. At present, the questionnaire only focuses on the perceptions around *continuation* of ADHD medication. Thus, it might be argued that the instrument only generates data consistent with the caregivers perception that significant others and groups will be supportive of their decisions regardless of what those decisions may entail.

Perceived behavioural control was not a significant predictor of intention in our model. This finding suggests that caregivers' beliefs about the control they have over the decision to medicate their children does not actually influence their behavioural intention.

The additional predictor we added to the standard TPB model, satisfaction with current ADHD medication, was a significant predictor of intention to continue medication. In fact, it was the second largest contributor to the model, explaining 7.2% of the variance in intention over and above that explained by the standard TPB components.

The addition of satisfaction as a separate predictor into the model requires some discussion. Our original intent was to combine satisfaction with current ADHD medication (as measured by the *ASK-ME* survey) to the attitude component of the TPB. Cronbach's α , as a measure of the internal consistency of that combination of items, produced an insufficient result of .081, however. Because previous literature indicated that the satisfaction variable is imperative to the decision to continue medication (dosReis et al., 2003; dosReis et al., 2009), we therefore decided to add it as a separate predictor variable in our regression model, rather than exclude it altogether because it did not fit statistically with any of the conventional TPB components.

As noted above, previous studies have emphasized the importance of satisfaction with current medication as a predictive factor in whether medication use will be continued. If caregivers of ADHD children choose medication to target a specific symptom and they see positive results, they are likely to display a positive attitude towards the medication and continue to use the treatment. Partial or no improvement of symptoms will encourage the discontinuation of medication (dosReis et al., 2009). Satisfied caregivers often feel that medication not only improves the quality of life for their child at home and at school, but also helps the family live a more normal or balanced life (Bastiaens, 2008; Neophytou & Webber, 2005).

Although the regression model based only on the conventional TPB components was a statistically significant good fit for the data and so did not necessarily need refining, adding the predictor variable of satisfaction with current medication use was crucial from the point of view of empirical knowledge derived from previous studies. Once that variable was included, the model explained almost 44% of the variance in intention to continue medication. Hence, this model can be used as a proficient determinant of caregiver's intention to continue medicating their ADHD child.

Caregiver and Child Attitudes towards ADHD Medication

Our data were consistent with previous literature suggesting that caregiver and child attitudes towards ADHD medication are different from one another (Efron et al., 1998). Specifically, it has been found that caregivers have a more positive attitude towards ADHD medication than their children do (McNeal et al., 2000; Stroh et al., 2008), a finding which is consistent with our data.

The agreement/disagreement between the caregiver's and child's perceptions varied across the PPHM and CPHM subscales of illness concern, perceived medication benefits, perceived severity of ADHD, and perceived cost and barriers of taking medication. Illness concern (i.e., the degree to which the caregiver and child worry about the negative effects of ADHD) was the only subscale of the PPHM and CPHM on which caregivers and children gave significantly discrepant responses. Our data suggested that caregivers were more concerned about their children's ADHD than the children themselves were. These findings stand in contrast to those of McNeal et al. (2000), who reported that caregivers and children did not differ in their perceptions of illness concern.

One possible reason for the discrepancy between our findings regarding illness concern and those of previous studies is that ours was a community, and not a clinic, sample. Thus, we assume that our caregiver participants were concerned enough about their child's ADHD to volunteer to participate in the study, and that therefore their concern might be greater than that of their non-volunteer counterparts. Therefore, their concern might also outweigh that of their children. The great caregiver concern about ADHD that we observed in our study is likely to motivate those individuals to seek and explore treatment plans, which is a positive outcome.

Caregiver's and child's perceptions of illness severity did not significantly disagree with one another. It has been found that throughout their formative years, children derive their attitudes and behaviours, at least somewhat, from the socialization they obtain from their caregivers (McNeal et al., 2000). Therefore, it seems likely that the children will adopt their caregivers' perceptions of illness severity, particularly because the mean age of the children was only 10.5 years. However, caregivers had a higher mean for perceived ADHD severity than their children did, and this perception of severity is necessary for medication continuation.

Caregivers and children did not significantly disagree on their perceptions of medication cost and barriers. Children, however, had a higher mean score for the perceived costs and barriers to taking ADHD medication subscale than their caregivers did. This could

possibly be explained by the fact that this subscale focuses on aspects such as taking medication at school, and on the child's perceptions of what their friends think about their ADHD medication use.

Limitations and Directions for Future Research

Although this study provides useful information with regards to the prediction of caregiver's intention to continue medicating their child with ADHD, there are some limitations in terms of generalizability. For instance, in terms of the demographics of our sample, we were only able to recruit White and Coloured families. Furthermore, and perhaps more important in terms of generalizability of our findings, our sample was biased in terms of socioeconomic status because we only had access to participants who use the Internet, attend private schools, and are members of ADHD support groups. This bias is also reflected by the fact that most of the participants were of middle-class social standing, and that almost three-quarters of them lived in suburban neighbourhoods. Therefore, the sample does not represent the general population of South Africa. Future research should attempt to accurately represent the demographics of this country as it is culturally diverse, and culture influences one's beliefs around, perceptions and reaction toward, and satisfaction of medication (dosReis et al., 2003).

A more theoretical and conceptual limitation of the study concerns the fidelity of the TBP framework. Within this framework, attitudes, subjective norms, and perceived behavioural control are postulated as three conceptually independent variables determining behavioural intention. However, in Liska's (1984) critique of the TPB, he highlights the fact that although these three components are *definitionally* independent, they are not *causally* independent. In other words, these components not only affect one another, but are also affected by the same social experiences. Therefore, it appears that the TPB oversimplifies the causal structure between the various components, and does not take into account that the same experiences can influence the different components.

Further with regard to critiques of the TPB, some authors (e.g., Sharma & Kanekar, 2007) note that it is not as powerful as other models might be because it does not take into consideration cultural factors, demographic variables, and personality-related variables, all of which also influence behaviour.

We anticipate that the results of this study will have the potential to be used to create interventions that will positively influence caregiver decision-making regarding continuation of their child's ADHD medication. However, as our sample size is relatively small, this study has relatively little statistical power, and future studies should rectify this by recruiting a

larger sample. Nonetheless, although we had a small sample size, the ratio for participants to independent variables (i.e., at least 5:1) for multiple regression was adhered to (Anderson & Lavalley, 2008). If our sample size was bigger, we would have been able to conduct a factor analysis, which may have elicited data with more fidelity and generalizability, as we would have been certain that the questionnaires and variables were really measuring what we claim they measure. Furthermore, a larger sample size would have permitted us to include more predictor variables in our study. For instance, we might have been able to investigate the effect of certain demographic variables on medication continuation; such investigations are important because, in the United States for example, attitudes towards medication have been found to be less positive amongst minority and lower-income neighbourhood groups (McLeod, Pescosolido, Takeuchi, & White, 2004).

Examining other potentially important variables, such as knowledge about medication, might also reveal interesting findings. The quality of caregiver knowledge about ADHD medication may affect the treatment plan and the compliance therewith (McNeal et al., 2000). Therefore, it is essential for caregivers to receive accurate knowledge about ADHD and the available treatments in order to assist them in selecting and maintaining the best treatment plan for their child. This will facilitate the continuation of medication (dosReis & Myers, 2008; Stroh et al., 2008). We did not add this important predictor variable to our study, but we advise future research in this field to include it.

Conclusion

This is the first study to identify factors (family attitude toward medication, subjective norms surrounding medication, and medication satisfaction) determining caregiver intention to continue medicating their child diagnosed with ADHD. We also presented a comparison between child and caregiver attitudes towards ADHD medication, and showed that caregivers and children disagreed on their concern with ADHD. This is one of few studies to consider the child's attitude towards their medication. A better understanding of the factors associated with medication continuation will lead to better implementations of interventions associated with adequate treatment plans. The results of this study could, for instance, be used to inform health-care providers about factors influencing the caregiver decision to initiate and to continue medicating ADHD children, and to thereby assist those providers in helping caregivers and children make the most appropriate choices for their circumstances.

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Appendix A

DSM-IV-TR Diagnostic Criteria for ADHD

I. Either A or B:

- A. Six or more of the following symptoms of *inattention* have been present for at least 6 months to a point that is disruptive and inappropriate for developmental level:

Inattention

Often does not give close attention to details or makes careless mistakes in schoolwork, work, or other activities.

1. Often has trouble keeping attention on tasks or play activities.
2. Often does not seem to listen when spoken to directly.
3. Often does not follow instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behaviour or failure to understand instructions).
4. Often has trouble organizing activities.
5. Often avoids, dislikes, or doesn't want to do things that take a lot of mental effort for a long period of time (such as schoolwork or homework).
6. Often loses things needed for tasks and activities (e.g. toys, school assignments, pencils, books, or tools).
7. Is often easily distracted.
8. Is often forgetful in daily activities.

- B. Six or more of the following symptoms of *hyperactivity-impulsivity* have been present for at least 6 months to an extent that is disruptive and inappropriate for developmental level:

Hyperactivity

1. Often fidgets with hands or feet or squirms in seat.
2. Often gets up from seat when remaining in seat is expected.

3. Often runs about or climbs when and where it is not appropriate (adolescents or adults may feel very restless).
4. Often has trouble playing or enjoying leisure activities quietly.
5. Is often "on the go" or often acts as if "driven by a motor".
6. Often talks excessively.

Impulsivity

1. Often blurts out answers before questions have been finished.
 2. Often has trouble waiting one's turn.
 3. Often interrupts or intrudes on others (e.g., butts into conversations or games).
- II. Some symptoms that cause impairment were present before age 7 years.
 - III. Some impairment from the symptoms is present in two or more settings (e.g. at school/work and at home).
 - IV. There must be clear evidence of significant impairment in social, school, or work functioning.
 - V. The symptoms do not happen only during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic Disorder. The symptoms are not better accounted for by another mental disorder (e.g. Mood Disorder, Anxiety Disorder, Dissociative Disorder, or a Personality Disorder).

Based on these criteria, three types of ADHD are identified:

1. ADHD, Combined Type: if both criteria 1A and 1B are met for the past 6 months
2. ADHD, Predominantly Inattentive Type: if criterion 1A is met but criterion 1B is not met for the past six months

ADHD, Predominantly Hyperactive-Impulsive Type: if Criterion 1B is met but Criterion 1A is not met for the past six months.

Appendix B

Recruitment Poster



ADHD, AUTISM, CAREGIVER STRESS?!!

Are you interested in finding out more about your child's disorder? Or how it may be affecting you?

Researchers at the University of Cape Town are conducting a study to understand how **Autism, Attention Deficit (Hyperactivity) Disorder (ADHD/ADD), normally developing children and the accompanying Caregiver Stress** affect the daily lives of the people involved. In addition to this, we are looking at aspects surrounding the **medication** of children with ADHD.

This study calls for the **participation of caregivers** of children who have been diagnosed as Autistic or ADHD/ADD as well as normally developing children. A **brief interview** with the **child** is also necessary. Participation in this study would be greatly appreciated.

The research consists of a maximum session of 1 hour for completing questionnaires on Caregiver Stress and ADHD Medication which can be emailed for your convenience.

If you are interested in taking part, or for additional information, please contact:

- **Jessica Cheesman on 0741331899**
jecheesman@gmail.com
- **Claudia Coetzee on 0835787722**
ctzcla002@uct.ac.za
- **Lesia Smith on 0722369868**
lesiasmith@gmail.com

Assent Form

Project Title:

Factors Influencing Caregiver Decision to Maintain Medicating Their Children Diagnosed with Attention-Deficit/Hyperactivity Disorder.

Principal Investigator: Jessica Cheesman

Why are you here?

“Your doctors/caregivers want to tell you about a research study involving children with Attention Deficit/ Hyperactivity (ADHD/ADD). Research is a special way to learn about something. They want to see if you would like to be in this study. Jessica Cheesman, Claudia Coetzee, and Lesia Smith are doing this study.”

Why is this study being done?

“Your doctors are doing this study because they want to learn more about how ADHD/ADD is affecting children’s lives, so that this can provide psychologists and psychiatrists with information that will help them to treat children with ADHD/ADD.”

What will happen to you if you agree join this study?

“If you take part you will be asked some questions about your feelings and your life. Your mom/dad will also be asked the same questions about you. But you will only be asked these questions if you join the study.”

“This study won’t make you feel better or get well. But the researchers might find out something that will help other children like you later.”

What if you have any questions?

“If you have questions about the study you can ask the researchers at any time. You can ask now. You can also ask later. You can talk to the researchers or you can talk to someone else. Do you have any questions now?”

Who will know you are in the study?

“When the study is finished we will tell other researchers, psychiatrists and psychologists what we found out, but we won’t tell them your name.”

Do you have to be in the study?

“You don’t have to be in the study. No one will be mad at you if you don’t want to do this. If you don’t want to be in this study, you just have to tell us. If you want to be in the study, you just have to tell us. You can say yes now and change your mind later. It is up to you.”

“If you want to be in this study print your name here”

I want to be in this study _____

Signature or Mark of Subject or Legally Authorized

Date

Representative

Signature of Person Assent Consent

Date

Witness to Assent if Subject is Unable to Read or Write

Date

(Must be different than the person obtaining assent)

Signed copies of this assent form must be 1) retained on file by the principal investigator, 2) given to the subject and 3) placed in the subject's medical record (when applicable).

Appendix D

Consent Form

Factors Influencing Caregiver Decision to Maintain Medicating Children Diagnosed with Attention-Deficit/Hyperactivity Disorder

Dear Caregiver

You are invited to take part in a research study. This form provides you with information about the study and seeks your authorization for the collection, use and disclosure of your mental health and other personal as other information necessary for the study. The Principal Investigator (the person in charge of this research) or a representative of the Principal Investigator will also describe this study to you and answer all of your questions. Your participation is entirely voluntary. Before you decide whether or not you want your child and yourself to take part, read the information below and ask questions about anything you do not understand. By participating in this study you will not be penalized or lose any benefits to which you would otherwise be entitled.

1. Investigators and Telephone Number(s)

Jessica Cheesman

Masters Student

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Kevin G. F. Thomas, Ph.D.

Senior Lecturer

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2. What is the purpose of this research study?

The purpose of this research study is to explore the factors that influence caregiver decisions to continue or discontinue medicating their child with ADHD.

3. What will be done if your child/adolescent takes part in this research study?

In this study, you and your child will both undergo an interview that will ask you questions relating to your child's mental health. In addition, you and your child will separately complete a questionnaire relating to your child's ADHD medication.

Possible locations for the interviews and filling out the questionnaires and completing the interviews are: the University of Cape Town's Department of Psychology or at your home. Each testing session will be individually conducted by a postgraduate psychology student who has been trained in the use of the measures that will be administered, and who is under the supervision of a clinical psychologist.

After the testing session, you will have the opportunity to ask questions and thus learn more about psychological research. However, your child's particular results will not be disclosed.

If you have any questions now or at any time during the study, you may contact the Principal Investigator listed in #1 of this form.

4. If you choose to allow your child to participate in this study, how long will he/she be expected to participate in the research?

The study consists of 1 session, which will last for a maximum of 2 hours. If at any time, during the interviews or when filling out the questionnaire, you or your child finds any of the procedures uncomfortable, you are free to skip that question, or stop entirely.

5. How many children are expected to participate in the research?

34

6. What are the possible discomforts and risks?

Possible discomfort your child may experience is slight fatigue. If he/she becomes tired during either of the interviews or when they are completing the questionnaire, we will take a break. Your child will be allowed to take breaks whenever requested. Your child may feel slight discomfort with the fact that he/she is taking part in an ADHD study and that people at the venue of the study may know of his/her ADHD diagnosis. However, privacy will be maintained, as best as is possible, in the place where the study is conducted. You may also feel some sadness or slight embarrassment over some of the questions.

If you wish to discuss the information above or any discomforts you or your child may experience, you may ask questions now or call the Principal Investigator listed on the front page of this form.

7a. What are the possible benefits to you and your child/adolescent?

You, your child and family may or may not personally benefit from the research. However we are happy to send you and any treatment professionals you may be working with feedback from your questionnaires, and this may assist you with finding a way forward.

7b. What are the possible benefits to others?

The objective is to be able to identify caregiving stress and the domain where this stress lies. The areas where their child is most severely functionally impaired will also be identified along with any other factors which contribute to the caregiving stress. This will allow for holistic family intervention plans to be developed which focus not only on the child but the caregiver as well, and aim to reduce stress and create a better living environment for all family members.

8. If you choose to take part in this research study, will it cost you anything?

Participating in this study will not cost you anything.

9. Will you receive compensation for taking part in this research study?

There will be no compensation for participation in this study.

10a. Can you withdraw your child from this study?

You are free to withdraw your consent and to stop participating in this research study at any time. If you do withdraw your consent, there will be no penalty.

If you have any questions regarding your child's rights as a research participant, and your rights as the individual granting consent for research participation, you may phone the Psychology Department offices at 021-650-3430.

10b. If you withdraw your child from this study, can information about you still be used and/or collected?

Information already collected may be used.

11. Once personal and performance information is collected, how will it be kept secret (confidential) in order to protect your privacy?

Information collected will be stored in locked filing cabinets or in computers with security passwords. Only certain people have the right to review these research records. These people include the researchers for this study and certain University of Cape Town officials. Your research records will not be released without your permission unless required by law or a court order.

12. What information about your child may be collected, used and shared with others?

The information gathered from your child will be on their mental health status and functional impairments related to ADHD or Autism. If you agree that your child can be in this research study, it is possible that some of the information collected might be copied into a "limited data set" to be used for other research purposes. If so, the limited data set may only include information that does not directly identify you or your child. For example, the limited data set cannot include you or your child/adolescents' name, address, telephone number, ID number, or any other photographs, numbers, codes, or so forth that link you or your child/adolescent to the information in the limited data set.

The results of the research will be presented as part of an Masters research project for the University of Cape Town. Also, the results may be submitted for publication in a peer-reviewed journal. In both instances neither you nor your child will be identified in any way.

13. What should you tell your child?

You may wish to discuss the study with your child to find out or determine whether he/she feels comfortable taking part. Your child should also know that if he/she does choose to participate, he/she can withdraw at any time during the study with no negative consequences

15. Signatures

As a representative of this study, I have explained to the caregiver/guardian of the participant the purpose, the procedures, the possible benefits, and the risks of this research study; and how the participant's performance and other data will be collected, used, and shared with others:

Name of Researcher and writer of thesis _____

Signature of Person Obtaining Consent and Authorization Date

You have been informed about this study's purpose, procedures, possible benefits, and risks; and how your child's mental health status and ADHD-related functional impairments and other data will be collected, used and shared with others. You have received a copy of this form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask other questions at any time.

You voluntarily consent to allow your child to participate in this study. You hereby authorize the collection, use and sharing of your child's mental health status and ADHD-related functional impairments and other data. By signing this form, you are not waiving any of your legal rights.

Name of Participant ("Study Subject") _____

Signature of Person Consenting and Authorizing Date

Please indicate below if you would like to be notified of future research projects conducted by our research group:

_____ (initial) Yes, I would like to be added to your research participation pool and be notified of research projects in which I or my child might participate in the future.

Method of contact:

Phone number: _____

E-mail address: _____

Mailing address: _____

Appendix E
Demographic Questionnaire

DEMOGRAPHIC QUESTIONNAIRE

1. Age :

2. Sex (circle one): Male Female

3. What is your race or ethnic background? (circle one)

WHITE

AFRICAN

COLOURED

ASIAN

OTHER : (SPECIFY)

4. Religion :

5. Home Language :

6. Marital status : (circle one)

MARRIED

DIVORCED

SEPARATED

SINGLE

7. Is your child on medication? (circle one) Yes No

8. Size of house (indicate the number of rooms in the house):

.....

9. Number of people who live in the house:

10.1 What term best describes the kind of neighbourhood in which you live:

SUBURBAN

URBAN

TOWNSHIP

10.2 What is the name of the neighbourhood in which you live?

.....

11. Household Income per annum (tick appropriate income category):

0-35000:.....

36000-50000:.....

76000-125000:.....

126000-175000:.....

176000-225000:.....

226000-275000:.....

276000-325000:.....

326000-375000:.....

376000-425000:.....

426000-475000:.....

476000-525000:.....

>526000:.....

EDUCATION LEVEL OF CHILD

12. Education (highest grade completed):

13. Has most of your child's schooling been in a rural or urban setting (circle one)?

RURAL

URBAN

14. Has he/she repeated any grades? YES NO

If yes, please specify which grade(s):

.....

15. What grade is your child presently in? (If not in school please indicate this):

.....

Appendix F

Subjective Norms Scale

THE SUBJECTIVE NORMS SCALE
PARTICIPANT NAME: _____

This questionnaire wishes to find out what YOU think OTHERS think about your decision to maintain medicating your child. Please tick the appropriate box indicating whether YOU think THEY would APPROVE or DISAPPROVE. If you are unsure about what THEY would think, tick the corresponding box (i.e. UNSURE). If these "OTHERS" are not available to you, tick NOT AVAILABLE.

For example:

If you think your pets will approve of you maintaining your child's medication, tick APPROVE.

If you think your pets will disapprove of you maintaining your child's medication, tick DISAPPROVE. If you are unsure whether your pets will approve/disapprove of you maintaining your child's medication, tick UNSURE. If you do not have pets, tick NOT AVAILABLE.

	NOT AVAILABLE	APPROVE	DISAPPROVE	UNSURE
Your spouse or partner				
Your caregivers				
Your relatives/kin (other than caregivers)				
Your spouse or partners caregivers				
Your spouse or partners relatives/kin				
Your friends				
Your spouse or partners friends				
Your own children				
Other caregivers				
Co-workers				
Caregiver groups				
Social groups/clubs				
Religious affiliations				
Your family or child's physician				
School				
Professional helpers (social workers, therapists)				
Your community				
The media				

Appendix G

Perceived Behavioural Control and Behavioural Intention Scale

Perceived Behavioural Control and Behavioural Intention scale (PBCBI)

Name of participant: _____

For each question circle the number that corresponds with your feelings in reference to the statements.

1= Strongly Disagree

2= Disagree

3= Neutral

4= Agree

5= Strongly Agree

1. I intend to maintain my child's ADHD medication.

1 2 3 4 5

2. It is necessary for my child to be on medication.

1 2 3 4 5

3. I intend to discontinue my child's ADHD medication.

1 2 3 4 5

4. Children with ADHD cannot function daily without medication.

1 2 3 4 5

5. I always do everything I can to ensure that my child takes his/her medication.

1 2 3 4 5

6. I am seeking alternative treatments to replace medication.

1 2 3 4 5

7. I have full control over deciding whether to keep my child on medication.

1 2 3 4 5