

Pharmacological interventions for ADHD: how do adolescent and adult patient beliefs and attitudes impact treatment adherence?

Suzanne McCarthy

School of Pharmacy, University
College Cork, Cork, Ireland

Abstract: Adherence to medication can be problematic for patients, especially so for patients with attention deficit hyperactivity disorder (ADHD). Effective medications are available for the treatment of ADHD; however, nonadherence rates for ADHD medication range from 13.2%–64%. The reasons for nonadherence can be complex. This review aims to look at how the beliefs and attitudes of adolescents and adults impact ADHD treatment adherence.

Keywords: attention deficit hyperactivity disorder, medication, stimulant, attitude, belief, adherence

Background

Attention deficit hyperactivity disorder (ADHD) is a common neurodevelopmental disorder characterized by symptoms of inattention, impulsivity, and hyperactivity.¹ The British Child and Adolescent Mental Health Survey, conducted in 1999, estimated the prevalence of ADHD in boys and girls aged 5–15 years to be 3.62% and 0.85%, respectively.² A recently published study by Russell et al³ used 2008/2009 data from the United Kingdom Millennium Cohort Study⁴ and estimated that the prevalence of parent-reported ADHD in children aged 7 years was 1.4%. It is reported that the prevalence of ADHD in children globally is approximately 5%.^{5,6} There is now consensus among experts that ADHD may currently affect at least 1%–2% of adults in the UK and 2%–4% worldwide.^{7–11}

As stated in the National Institute for Health and Care Excellence (NICE) guidelines published in 2008 and modified in 2013,¹² diagnosing ADHD requires an understanding of normal child/adolescent development, and it requires differentiating between the behaviors and symptoms of ADHD from normal developmental features and from other disorders such as autism. In addition, it requires the identification of evidence from the social context that may impact on behavior, and it also requires an ability to identify predisposing medical factors such as fetal alcohol syndrome, extreme prematurity, and to identify coexisting conditions such as mood disorders, anxiety, epilepsy, and nocturnal enuresis.¹³ It is also important to exclude conditions that may cause ADHD-like symptoms such as sleep disorders^{14,15} and obstructive sleep apnea syndrome.¹⁶

The NICE guidelines also include recommendations for the treatment of ADHD across the lifespan.¹² Pharmacological treatment is not recommended for the treatment of ADHD in preschool children, nor is it recommended as a first-line treatment in all

Correspondence: Suzanne McCarthy
School of Pharmacy, Cavanagh Pharmacy
Building, University College Cork,
College Road, Cork, Ireland
Tel +353 21 490 1714
Email s.mccarthy@ucc.ie

school-age children and young people with the condition. Medication does play a role in the management of those children with severe symptoms and impairment, and for children who do not respond sufficiently to educational or psychological treatment.¹²

ADHD treatment includes pharmacologic and nonpharmacologic approaches; this article will examine how patient beliefs and attitudes impact on adherence to the pharmacological treatments available to treat ADHD in adolescents and adults. The pharmacological management of ADHD can largely be divided into stimulant and nonstimulant treatment.

Central nervous system stimulants

In the UK, the central nervous system stimulant treatments licensed for the treatment of ADHD in children and adolescents are methylphenidate, dexamfetamine, and lisdexamfetamine.

Methylphenidate

Methylphenidate is licensed as part of a comprehensive treatment program for ADHD in children aged 6 years of age and over when psychological, educational, and social measures prove insufficient.¹⁷ It is available in a range of immediate release (Ritalin[®], Medikinet[®], Equasym[®], Tranquilyn[®], and generic methylphenidate) and extended release preparations (Concerta XL[®], Matoride XL[®], Medikinet XL[®], and Equasym XL[®]). Methylphenidate is not licensed for the initiation of treatment for ADHD in adults. Concerta XL[®] is currently the only methylphenidate preparation that is licensed as a continuation treatment; it is used for patients who started treatment prior to adulthood, who showed a clear benefit from the treatment, and whose symptoms continue into adulthood.¹⁸

Dexamfetamine/lisdexamfetamine

Dexamfetamine is licensed for the treatment of refractory hyperkinetic states in children from 3 years of age. It is licensed in adults only in the treatment of narcolepsy.¹⁹ Lisdexamfetamine dimesylate (Elvanse[®]), which received its UK marketing authorization in February 2013, is a prodrug comprised of dexamfetamine covalently bonded to the amino acid, l-lysine. It is indicated as part of a comprehensive treatment program for ADHD in children aged 6 years of age and over when response to previous methylphenidate treatment is considered clinically inadequate. It is also indicated as a continuation treatment in adulthood, when symptoms in adolescents persist into adulthood and where patients have shown clear benefit from treatment.²⁰

Nonstimulant treatment

Atomoxetine

Atomoxetine is the only nonstimulant licensed for the treatment of ADHD in children aged 6 years and older, in adolescents, and in adults as part of a comprehensive treatment program. In 2013, atomoxetine gained marketing authorization for use as initiation treatment in adults, the only such licensed treatment for adult ADHD in the UK.²¹ As part of the diagnostic process, the presence of symptoms of ADHD that were preexisting in childhood should be confirmed.²¹

Efficacy of pharmacological treatment

Numerous randomized controlled trials have been performed to determine the efficacy of medication in the treatment of ADHD in children, adolescents, and adults; the results demonstrate that pharmacological treatment is effective in reducing the core symptoms of ADHD in patients.¹² However, many of these studies have been conducted over a relatively short duration of time. Far fewer long-term studies have been conducted; reviews of this literature have revealed that although ADHD medications are more efficacious than placebo, the evidence base is sparse. In addition, nonadherence to medication in the long term is identified as a significant limitation.²² The issue of nonadherence in ADHD is of particular importance, as ADHD is no longer thought of as a condition confined to childhood, but as one that for many patients is chronic and persists into adolescence and adulthood.²³

Medication-taking behavior

There are many terms cited in the literature, often defined differently and used interchangeably, to describe medication-taking behavior by patients.²⁴ Compliance is defined as “the extent to which the patient’s behaviour matches the prescriber’s recommendations”,²⁵ whereas adherence refers to “the extent to which a person’s behaviour-taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider”.²⁶ Concordance relates more broadly to the nature of the interaction between the doctor and patient,²⁷ and it promotes the idea that the prescriber and patient should come to an agreement about the regimen that the patient will take.²⁸

In 2012, the ABC (Ascertaining Barriers to Compliance) Project published a new taxonomy for medication-taking behavior.²⁴ As part of this work, they defined adherence to medications as:

[...] the process by which patients take their medications as prescribed, composed of initiation, implementation and discontinuation.²⁴

Adherence has been described as “the key mediator between medical practice and patient outcomes”,²⁹ and health care professionals are more aware of the importance of adherence in achieving optimal therapeutic outcomes. However, it can often be difficult for health care professionals to understand the reasons for nonadherence among patients because the causes are often multidimensional. Adherence is influenced by many factors: the health care team and system-related factors; condition-related factors; characteristics of therapies; and patient-related factors.²⁶ These factors alone or in combination can lead a patient to become nonadherent. Nonadherence can also be categorized as unintentional and intentional—the former caused by factors such as poor memory and dexterity, or cost of medicines, whereas the latter reflects patients’ own beliefs and decision-making abilities. Horne and Weinman³⁰ describe how in chronic disorders, the belief held by a patient about their treatment can be a significant predictor of adherence to that treatment. The decision to take a medication is complex, and there may be instances where unintentional and intentional nonadherence interact.²⁵

Nonadherence levels to ADHD medication

Rates of nonadherence to ADHD medication, as reported in the literature, are variable and depend on how adherence is measured, the study setting (for example, controlled or community samples), and the duration of follow up. A recently published review on the topic reported mean nonadherence rates for ADHD medication ranging from 13.2%–64%.³¹ A number of studies have reported on factors that predict low adherence among different populations and across different ages of patients, including patients of older ages, those with a later onset of ADHD, those with a previous family history of ADHD, those with a paternal education level of college or higher, a higher methylphenidate dose,³² illicit substance abuse,³³ female sex, newly diagnosed patients, those with a high score on the Drug Use Screening Inventory revised version psychiatric disorder scale, and subjects with high educational degrees.³⁴

In the NICE ADHD guidelines,¹² suggestions provided to improve adherence to pharmacological treatment include:

- Improved communication between the prescriber, the patient, and the patient’s parents or partner (in the case of adult patients).
- Providing clear instructions about how to take the drug, which may include information on dose, duration, side effects, and dosage schedule.
- Peer support groups for the child or young person with ADHD and their parents or caregivers.
- Simple drug regimens (for example, once-daily modified-release doses).
- Encourage children and young people with ADHD to be responsible for their own health, including taking their medication.
- Advice on visual reminders to take medication regularly (for example, alarms, pill boxes).
- Incorporating medication taking into daily routines (for example, before meals or after brushing teeth).
- Where necessary, health care professionals should help parents or caregivers develop a positive attitude and approach in the management of medication, which might include praise and positive reinforcement for the child or young person with ADHD.

While many of these recommendations will aid in improving unintentional nonadherence to medication, there is little guidance on addressing intentional nonadherence.

It is important for a clinician to understand the factors that contribute to nonadherence of medication in order to help patients increase medication adherence; however, not all factors are modifiable (for example, age, family history, and so on). However, the attitudes of patients toward medication for ADHD are potentially modifiable and, therefore, this review will seek to examine literature on patient-related factors, particularly patient beliefs and attitudes, and the impact that these may have on intentional nonadherence in the context of ADHD. This review will also specifically focus on patients who have more autonomy over their medication-taking behavior: adolescents and adults with ADHD.

Methods

A literature search was conducted using PubMed, Embase, and PsycINFO databases with no restrictions on the date of publication. The following strategy was employed. Search terms:

1. Attention deficit hyperactivity disorder OR ADHD OR hyperkinetic disorder
2. Methylphenidate OR ritalin OR stimulant OR psychostimulant OR pharmacological treatment
3. Adherence OR compliance OR concordance OR medication adherence OR treatment adherence OR continuity OR discontinuity
4. Attitudes OR beliefs OR experiences OR perceptions OR knowledge OR preference.

These search terms were then combined using the AND function. A search, using the same terms, was also conducted using Google Scholar. The references of each of the studies

retrieved were hand-searched to identify any further relevant literature.

Studies were included if they made reference to the attitudes or beliefs of adolescent or adult ADHD patients toward pharmacological interventions, and if the studies addressed any impact these had on adherence to treatment. For the purposes of this study, adolescence was denoted as age 13 years and above, or where the study authors referred to adolescent patients. Studies were also included if the majority of participants were in their adolescent years.

The following citations were excluded: review articles; conference presentations; practice guidelines; and commentaries. Articles in which the full text was not in English were excluded. Studies that did not explore adolescent or adult patients' attitudes/beliefs (for example, only including caregivers) were also excluded.

Results

Sixty, 28, and 44 articles were retrieved from the PubMed, Embase, and PsycINFO searches, respectively. Duplicates were removed (number [n] =15). The titles and abstracts of the remaining 117 articles were reviewed applying the inclusion and exclusion criteria. Searching the references for relevant articles, a total of 14 articles were retrieved and included in this review.^{35–48}

Charach et al³⁵ conducted qualitative interviews with 12 adolescents (six males, six females) aged 12–15 years, as well as their parents. With regards to medication use, four major themes emerged; the first of these was the benefit derived from medication, mainly in relation to school or completing homework. Other participants reported that medication enhanced their confidence in school, as well as enhancing social relationships. The second theme was of medication and the effects on sense of self. Concerns were raised on how the medication changed who they were and in some cases made them less sociable. The third theme reported on adverse effects of medication including difficulty sleeping, low appetite, mood swings, and stomach aches. The impact of these adverse effects included adjusting the doses of medication, discontinuing medicines and trying other medications, and discontinuing medicines altogether. The final theme related to discontinuing medication. The sample of interviewees included a mix of patients who were taking medication, patients who had stopped and restarted medication, and patients who had stopped medication. Reasons for discontinuing medication included adverse effects, insufficient benefit, and changes to the patient's sense of

self. Some participants spoke of resisting medication use through noncompliance and expressed their desire to stop medication in the future. There were some young people who reported satisfaction with their medication and were adherent with its use.

Bussing et al³⁶ conducted a mixed-methods study on the willingness to use ADHD treatments, and sought the perceptions of four different stakeholder groups: adolescents (ranging from 14–19 years); parents; health professionals; and teachers. A total of 148 adolescents completed the study. The main findings were that adolescents expressed significantly lower willingness for ADHD interventions (both pharmacological and psychosocial) compared to the adult respondents. Willingness to use medications was increased when participants felt knowledgeable, and considered medications as acceptable and helpful. Willingness to use medication was decreased if participants anticipated side effects to the medication. Adolescents' previous experience with ADHD treatment did not increase their willingness to use any treatment modality – the authors suggested a number of reasons for this, including that adolescents may not have been involved in ADHD treatment discussions as children and thus would not have “a cohesive conceptual memory of the treatment experience”.³⁶

Walker-Noack et al³⁷ conducted six focus groups with young people aged 10–21 years diagnosed with ADHD. The focus of the discussion was on the perceptions of the young people toward ADHD and the barriers to treatment. Participants in all six focus groups identified a number of positive aspects relating to medication such as a decrease in hyperactive and impulsive symptoms and an increase in attention. Participants also perceived medication to be superior to behavioral treatments in terms of treating the core symptoms of ADHD. Despite this, the negative aspects of medications significantly outweighed the positive aspects of medications, according to the participants. Issues emerging from the discussions included negative physiological and psychological effects, such as loss of appetite and weight loss; general side effects such as nausea, headaches, and mood swings; depletion of energy affecting school performance; effects of depleting medication and subsequent extreme changes in hyperactivity; unpleasant taste and difficulty swallowing the medication, particularly among younger participants; negative effect on sleep, mostly causing difficulty falling asleep; social stigma associated with taking medication; hassle associated with adjusting medication doses; and decreased ability to be talkative. The authors suggest that the complex views of

ADHD and its treatment held by young people may be defined as barriers to treatment adherence.³⁷

Knipp³⁸ conducted a qualitative study on the perceptions of 15 teenagers (aged 14–17 years) regarding ADHD and medication. The interviews, exploring the adaptation to ADHD, were guided by a priori categories which were derived from the Roy Adaptation Model.⁴⁹ In terms of physiologic–physical mode, the participants felt that once they had found the right medication, the effects were positive and the medication worked. The benefits of medication were such that participants reported that they would not stop taking medication despite the hassle of taking medications, or given the side effects associated with the medication. Participants reported an overwhelmingly positive effect of medications on school and school work. The majority of participants felt that they had positive interactions with family and with friends; these participants also reported experiencing positive results with the medications. In terms of self-concept, most participants had positive attitudes about themselves. These subthemes contributed to the overall theme recognized by the author as being that “meds help me”.³⁸

Travell and Visser³⁹ conducted qualitative interviews with 17 young people aged between 11 years and 16 years, along with their parents, the aim of which was to explore the longer-term outcomes of ADHD diagnosis and treatment. The authors report their findings in terms of five areas: the symptoms of ADHD and their consequences; the process of diagnosis and treatment; interventions; a personal diagnosis; and participation and voice. In terms of medication, participants reported both positive and negative aspects. Participants reported that on the one hand, medications improved their behavior and improved their concentration, both of which resulted in the young person getting into less trouble at school, while on the other hand, medications were associated with side effects, as well as with concerns about the psychological and physical effects of taking the medication. Some participants felt that taking medication led to issues regarding their identity, that they did not feel like themselves when they were taking the medication, as well as to issues of control in that the medication was controlling them. This led to an even divide in terms of those participants (and their parents) that had positive and negative views of the medication. In terms of the long-term use of medications, many young people wanted to, or thought that they would be able to, stop taking medication when they finished school; however, some believed that they would always

have to take the medication. The authors state that their data provided “considerable evidence regarding a reliance of medication, the taking of which might be difficult to relinquish in the future, combined with fear of the future and a desire among young people not to have to take medication indefinitely.”³⁹

Wong et al⁴⁰ conducted face-to-face interviews with 15 young people aged 15–17 years. Participants were recruited according to the following categories: those who continued taking medication for ADHD, and who had not attempted stopping treatment; those who had successfully stopped taking ADHD medication; and those who had not been successful in stopping treatment. The authors sought to explore issues such as adherence to medication, medication-related problems, beliefs about medications, quality of life, as well as the process of medication cessation. In terms of beliefs about ADHD medication, participants described the positive effects of the medication, in that the medication improved symptoms and improved the patients’ relationships; in some cases, participants felt that although they did not notice any changes themselves, others around them – such as their parents and teachers – noticed the difference. When discussing the negative aspects of medication, participants reported side effects such as appetite suppression and sleep disturbance. Participants also reported psychological side effects such as feeling spaced out and an inability to daydream. Many of the participants reported that the inconvenience of having to take medication on a daily basis was a negative aspect of treatment. Examining the issue of treatment adherence, the authors reported that the reasons for nonadherence could be categorized as unintentional and intentional; the former due mainly to forgetting doses, the latter often due to drug holidays. Apart from drug holidays, factors for intentional nonadherence included a dislike for taking medicines, the inconvenience of taking multiple daily doses, as well as side effects associated with the medication. It was also noted that side effects were sometimes reported by participants as an excuse for not taking medication. Ten participants had stopped taking medication – five of whom remained off treatment, and five of whom restarted medication. These participants were asked about their reasons for treatment cessation; seven reported that the decision to stop treatment was their own. The most common reasons to stop medication were participants’ desire to gain control over their condition and a desire not to continue taking medication. For the remaining three patients, they stopped taking medication as they no longer had access to treatment

services. The authors also reported that for some patients, intentional nonadherence was a precursor to the unplanned cessation of treatment.⁴⁰

Brinkman et al⁴¹ conducted focus groups with adolescents aged between 13 years and 17 years with ADHD. Seven focus groups were conducted with a total of 44 adolescents in order to gain an understanding of the participants' views of ADHD and their evolving role in managing their medication. One of the major themes that emerged was that adolescents assessed the impact of ADHD and medication by comparing periods on and off treatment. The authors reported how some participants described problems occurring due to ADHD, and/or they also described the benefits of medication, whereas other participants described how they did not experience problems occurring due to ADHD, and/or they did not benefit from medication. These contrasting views were discussed across a number of domains such as school, social interactions, personality, creativity, and driving. Another theme that emerged was the involvement of the adolescent in discussions and decision making. Categories within this theme included contributor to dosage adjustments, gaining a voice, covert medication disposal, and overt trials on and off medication. Many of the adolescents reported that, as they become more involved in decisions made about treatment, they experimented with stopping their medication. The final main theme was that of autonomy. As adolescents became older, they made more deliberate decisions, often to stop taking their medication. Categories included the selective use of medicine (for example, perceived need), future medicine use (for example, whether to continue taking their medicine), and trade-offs (for example, improvements in symptoms versus side effects).⁴¹

Davis-Berman and Pestello⁴² conducted interviews with 20 college students to explore the issue of taking medication for ADHD. Five themes emerged from the data: recruitment of young individuals; freedom from personal stigma; social issues surrounding stimulants; side effects; and abuse. When discussing stigma, participants did not report that stimulants reflected negatively on their sense of self. Mostly participants were not concerned with the stigma associated with taking medicine, although some did report feeling embarrassed at having to take medication. Participants did report that they experienced negativity and stigma from others toward ADHD and its validity as a condition. Participants did report many side effects associated with their medication, ranging from physical side effects such as weight loss and sleep problems,

to psychological side effects such as personality changes and feeling different. Experiencing these side effects resulted in many people taking drug holidays on the weekends and during holidays.⁴²

Pillow et al⁴³ conducted a survey with 193 university students, ranging in age from 18–28 years, who had a self-reported diagnosis of attention deficit disorder or ADHD and a history of stimulant treatment. The survey had been developed by the study authors based on previous unpublished work. Using factor analysis, the participants' attitudes and decisions regarding stimulant use were represented by four factors: "improved attention/academics"; "social self-enhancement"; "loss of authentic self"; and "common side effects". The first two factors describe the benefits of treatment that the participants reported; participants reported that medication improved the core symptoms of ADHD, along with academic performance, and this factor had the largest effect when distinguishing between current and past users of stimulants. Many of the participants who were current users of stimulants also reported that the medication improved their social self; this factor also differentiated between participants who were current users of stimulants and those who were not. The costs associated with stimulant use are represented by the factors "loss of authentic self" and "common side effects". The authors report that "loss of authentic self" differentiated between those who continued treatment and those who stopped medication, whereas "common side effects" such as loss of appetite and difficulty in sleeping did not.⁴³

Meaux et al⁴⁴ conducted interviews with 15 college students with ADHD aged between 18 years and 21 years. The purpose of the study was to explore the reasons why participants continued or discontinued the use of stimulant medication. Of the 15 participants, ten continued to use stimulants with the remaining five having discontinued medication. Three themes emerged from the data: the first of these was labeled "the early years"; the second theme was labeled "the trade-off"; and the third theme was the use of "stimulant medications in college". When talking about the early years, participants discussed medication taking during school and switching stimulants, primarily due to the advent of extended release preparations. Over half of the participants stopped taking medication between the seventh and ninth grade; the decision to stop was typically made by the participant, while some consulted their parents. Four participants had never stopped taking medication, but they regularly forgot to take it. Two participants continued to take medication regularly throughout high school, describing how the medication helped with school work and concentration.

Participants reported having negative feelings toward taking medication while at school, given that they were singled out and embarrassed at having to go to the office to receive the medication. In terms of the second theme of “the trade-off”, participants discussed the general effects, side effects, and benefits of stimulant medication. Several of the participants reported that the medication made them less sociable; however, those participants who received a diagnosis later on felt more positively toward the social effects of their medication. All of the participants discussed the negative physical (for example, nausea or insomnia) and psychological side effects (irritability, anger, restlessness, or depression) of the stimulants. In terms of the benefits of medication, participants reported improvements in concentration and focus, which subsequently enabled them to study for longer and to complete more school work. Improvements in concentration while driving were also reported. The final theme, “stimulant medications in college”, was discussed in terms of the decision to take medication, monitoring and health care, and misuse and abuse. Of the 13 participants who had previously stopped taking medication, eight had restarted and cited that medication was necessary for them to study and to get things done. Many of the participants reported that they only took medication when they perceived a need for the medication (for example, when they had work that needed to be done). The two participants who had not stopped taking medication reported the benefits of medication in all aspects of their lives. The authors highlighted the interesting point that health care providers were rarely involved in decisions to stop or restart medication, and that many participants discussed how they had very little engagement with their physician. In terms of stimulant misuse and abuse, several participants referred to a reluctance to inform people of their ADHD, as they did not want to be seen “just wanting the drugs”.⁴⁴

O’Callaghan⁴⁵ conducted a mixed-methods study investigating issues associated with stimulant adherence among adults with ADHD. The quantitative phase of the study, which was conducted with 67 adults aged between 19 years and 64 years, gathered data on quality of life through the administration of the adult ADHD quality of life questionnaire and data on adherence to medication through self-report. The qualitative phase of the study involved semistructured telephone interviews with 18 of the adults in order to explore patients’ experiences of stimulants in the context of the Health Belief Model, in which certain variables (perceived benefits of treatment, perceived barriers of treatment, perceived severity of the condition, cues to action, and self-efficacy) are considered to influence whether a patient

will adhere to medication.⁵⁰ The author described many of the findings in the context of participants reporting a low or high ADHD-related quality of life, these data were gathered from the quantitative phase of the study. When discussing the benefits of treatment, participants referred to an increase in positive behaviors (participants with high ADHD-related quality of life) or a reduction in negative behaviors (participants with low ADHD-related quality of life). All of the participants discussed the barriers associated with stimulant treatment: physical side effects (for example, insomnia and weight loss) were largely reported by participants with high ADHD-related quality of life as effects that they both expected and could control; psychological side effects (for example, feeling anxious, irritable, or feeling flat) were reported only by patients with a low ADHD-related quality of life; in some cases, participants discontinued medication due to these psychological side effects. A lack of effectiveness, the fear of cardiac-related side effects, difficulty getting prescriptions dispensed, and the cost of medications were also reported as barriers. In terms of the severity of the condition, participants discussed the consequences of untreated ADHD on college, employment, finances, and relationships. These negative experiences were deemed to have directly influenced the participants’ decision to take medication. Cue to action was discussed in terms of patients’ relationship with their physician; those with high ADHD-related quality of life reported positive health outcomes as a result of positive relationships with their physician. By identifying the correct medication and dose, physicians lowered the patients’ perceived barriers to medication use. Conversely, patients with a low ADHD-related quality of life reported dissatisfaction with their physician, which was independent of whether the patients were adherent to their medication. Self-efficacy was only reported by one participant in that she did not attend her monthly appointments with her physician due to a lack of confidence which, in turn, resulted in a negative experience with her medication.⁴⁵

Matheson et al⁴⁶ conducted semistructured interviews with 30 adults with ADHD to explore a number of issues related to ADHD, including the participants’ experiences of pharmacological treatment. The participants were comprised of adults, whose diagnosis and treatment for ADHD started before the age of 18 years, as well as adults who were diagnosed and treated for ADHD after the age of 18 years. Within each of these groups, there was a mix of participants who had not had a break from treatment, and those who had periods of 6 months or more without treatment. One of the themes that emerged from the study was that participants weighed up the

benefits and costs of pharmacological treatment. The benefits of treatment included that medication lessened the chaos associated with ADHD, as well as improvements in cognition and in focus relating to work or college. Some participants also reported that medication improved their ability to function in social settings. In terms of the costs associated with ADHD medication, many participants reported on the physical side effects such as insomnia, poor appetite, and headaches, and psychological side effects such as paranoia, loss of self-identity, and sociability. Some participants described how medication effectiveness was reduced in the long term, necessitating frequent drug changing, while others reported that they did not receive sufficient specialist support to find the optimum treatment. It was also felt by some participants that psychiatrists had overly high expectations of the effectiveness of medication. While many participants felt that pharmacological therapies had a place in treatment, it was not effective alone; the participants also felt that they required additional educational and psychosocial support. When the issue of nonadherence was explored, the most commonly cited reason was forgetfulness. This was followed by taking medication only when there was a perceived need, wanting to take drug holidays, and a perceived lack of guidance from clinicians. For participants who stopped taking medication for longer periods, the reasons provided were the occurrence of side effects, uncertainty over the effectiveness of medication, and loss of self-identity. When participants did stop medication, they reported that this was associated with increased behavioral problems, anger, and frustration – all of which had a negative impact on their home, work, and school life.⁴⁶

The final two studies^{47,48} examined the attitudes of patients with ADHD toward their medication in order to develop various instruments. The first study by Ferrin et al⁴⁷ examined the attitudes of adolescents with ADHD toward medication adherence in order to develop the questionnaire on attitudes toward treatment of ADHD (QATT) questionnaire. The 33-item questionnaire was initially developed from the literature and from clinician input. Following an initial pilot conducted with 20 adolescents, the questionnaire was applied to 120 adolescents with ADHD and their parents. The authors reported on three main factors relating to attitudes toward medication. These were, firstly, the concerns that adolescents had about current and future side effects associated with medication; secondly, the insight toward illness and the necessity for medication and professional help; and lastly, adolescents' self-perception and the patient–doctor relationship. The global score on the QATT questionnaire was able to differentiate between good and poor adherents, although

not for each of the factors within the scale. The authors proposed a number of reasons why this could be the case, including the fact that the scale measured attitudes toward medication rather than actual adherence, and the inability to accurately monitor adherence. Although there are a number of documented limitations with the questionnaire, the authors propose that further work should be done to explore the potential for its use in exploring attitudes toward medication and in predicting treatment adherence.⁴⁷

The second of these studies was conducted by Cox et al⁴⁸ in order to test the relationship between the perceived consequences of ADHD medication and its use through the ADHD Medication Attitudes Scale (AMAS), as well as through self-reported medication usage. The authors reported on data from 356 participants aged from 13–62 years. Following analyses of the data, the questionnaire was reduced from 27 to 22 items. The authors reported that factor analysis revealed two factors: one indicating positive and one indicating negative attitudes toward medication. Predictors of self-reported adherence to medication included more positive attitude, less negative attitude, and older age (+19 years), independently.⁴⁸

Discussion

Adherence to medication is a complex issue, particularly in the area of psychotropic drug use. The available literature would suggest that when making decisions about medication, adolescents and adults with ADHD balance the positives and negatives, behavior described by the health beliefs model.⁵¹ Participants reported the positives of medication in improving the core symptoms of ADHD, helping with school/college/work, and improving social relationships, along with the negatives of medication, which included the physical side effects, the effects on sense of self, a loss of personality, the stigma associated with medication use, and the inconvenience of taking medication. It has been observed, particularly among studies of adolescents, that patients desired more autonomy and control over their condition, prompting them to make decisions about medication treatment.^{38–41} When patients stopped taking medication, typically in adolescence, the decision was one that they often made themselves. Reasons included not wanting to take medication indefinitely, not perceiving a need for medication, a perceived lack of efficacy, and feeling that other negatives associated with medication outweighed the positives. Stopping treatment may take the form of unplanned drug holidays or complete treatment cessation. However, in some of the studies, patients reported restarting medication either on a continuous basis or on an “as-required” basis.^{39,44,46} This was often due to issues

related to untreated ADHD, such as the impact on college work, employment, finances, and relationships. When restarting treatment, access to services was highlighted among some young people as an issue, and indeed for some people, difficulty accessing services was the reason for treatment cessation.^{40,45}

What can be done to improve adherence to stimulants? Firstly, it is important for the clinician to engage in discussions with the patient and their parents/spouse/partner, and so on, on issues of medication adherence. Safren et al⁵² suggest that a straightforward self-report measure may be a useful method to assess adherence to ADHD medications, particularly for adult patients. For issues relating to unintentional nonadherence (for example, forgetting to take medication), suggestions included in the NICE guidelines,¹² such as simplifying dosage regimens and reminders, could be adopted. When examining intentional nonadherence, it is important for clinicians to address concerns around side effects, as this was commonly cited in the literature as a reason for stopping treatment.^{35–37,39,40,42–47} Some of these side effects, particularly the physical side effects, may be minimized by a change of dose or medication.⁵³ Discussions should also focus on the psychological side effects, such as a loss of sense of self and changes related to personality, which were raised by participants in a large number of studies; in some cases, these side effects were deemed more troublesome than the physical side effects, often leading to treatment cessation.^{35,39,42,43,45,46} It is important to consider both patient and family preference for treatment; this is especially important for the adolescent and young adult patient who may wish to become more involved in the decision-making process. Instruments such as the QATT,⁴⁷ AMAS,⁴⁸ and the Southampton ADHD Medications Behavior and Attitude scale⁵⁴ may have the potential to facilitate clinicians with this process; however, further research is required on the use of these scales. In many of the studies identified, participants referred to taking stimulant treatment on an “as-required” or “pro re nata” (prn) basis. Caisley and Müller⁵⁵ provided a systematic review of the literature on the prn dosing of psychostimulants in adults with ADHD. Their findings suggest that there is a scarcity of data available on this method of dosing, and they call for further research to compare the effectiveness of regular and prn psychostimulant use.⁵⁵ In terms of stigma, Bussing and Mehta⁵⁶ provided a review of the literature on stigmatization and self-perceptions of youth with ADHD. They concluded that stigma experiences associated with ADHD have the potential to detrimentally affect treatment and outcomes, and that we require better

tools to “assess, address, and prevent” this from occurring.⁵⁶ Integral to the strategies mentioned earlier is education and the doctor–patient relationship. The clinician has a prominent role to play in providing appropriate education and support to patients and their families about ADHD and the various treatment options available. Theoretical models of health behavior, such as the transtheoretical model of change, may be useful to the clinician to guide patients and their families during this process.⁵⁷ In terms of medication, issues about their effectiveness, side effects, as well as whether to continue/discontinue medication should be discussed and monitored regularly.^{57,58} Discussing this information and involving patients and families in decision making is important for the successful management of ADHD.⁵⁹ This is required both at treatment initiation as well as throughout treatment in order to encourage long-term adherence to medication.⁵⁸ Finally, whether adolescents decide to continue taking treatment into adulthood, or whether they decide to stop treatment and possibly restart medication at a later point, it is important that appropriate transition service provision is available so that patients with ADHD avoid what Young et al⁶⁰ refer to as the “twilight zone”.

Disclosure

The author has received research funding from Shire Pharmaceuticals and has given talks at educational events sponsored by Shire Pharmaceuticals. The author reports no other conflicts of interest in this work.

References

1. Asherson and Kuntsi. Unravelling the complexity of attention-deficit hyperactivity disorder: a behavioural genomic approach. *Br J Psychiatry*. 2005;187:103–105.
2. Ford T, Goodman R, Meltzer H. The British Child and Adolescent Mental Health Survey 1999: the prevalence of DSM-IV disorders. *J Am Acad Child Adolesc Psychiatry*. 2003;42(10):1203–1211.
3. Russell G, Rodgers LR, Ukoumunne OC, Ford T. Prevalence of parent-reported ASD and ADHD in the UK: findings from the Millennium Cohort Study. *J Autism Dev Disord*. 2014;44(1):31–40.
4. Hansen K, Joshi H. *Children of the 21st century: The first five years*. London: The Policy Press; 2010.
5. Polanczyk G, de Lima MS, Horta BL, Biederman J, Rohde LA. The worldwide prevalence of ADHD: a systematic review and meta-regression analysis. *Am J Psychiatry*. 2007;164(6):942–948.
6. Polanczyk GV, Willcutt EG, Salum GA, Kieling C, Rohde LA. ADHD prevalence estimates across three decades: an updated systematic review and meta-regression analysis. *Int J Epidemiol*. 2014;43(2):434–442.
7. Kooij SJ, Bejerot S, Blackwell A, et al. European consensus statement on diagnosis and treatment of adult ADHD: The European Network Adult ADHD. *BMC Psychiatry*. 2010;10:67.
8. Rösler M, Casas M, Konofal E, Buitelaar J. Attention deficit hyperactivity disorder in adults. *World J Biol Psychiatry*. 2010;11(5):684–698.
9. Asherson P. Clinical assessment and treatment of attention deficit hyperactivity disorder in adults. *Expert Rev Neurother*. 2005;5(4):525–539.

10. Fayyad J, De Graaf R, Kessler R, et al. Cross-national prevalence and correlates of adult attention-deficit hyperactivity disorder. *Br J Psychiatry*. 2007;190:402–409.
11. Simon V, Czobor P, Bálint S, Mészáros A, Bitter I. Prevalence and correlates of adult attention-deficit hyperactivity disorder: meta-analysis. *Br J Psychiatry*. 2009;194(3):204–211.
12. National Institute for Health and Clinical Excellence. *Attention Deficit Hyperactivity Disorder: Pharmacological and Psychological Interventions in Children, Young People and Adults. (Clinical Guideline 72)*. London, UK: The British Psychological Society and the Royal College of Psychiatrists; 2008.
13. Esposito M, Gallai B, Parisi L, et al. Visuomotor competencies and primary monosymptomatic nocturnal enuresis in prepubertal aged children. *Neuropsychiatr Dis Treat*. 2013;9:921–926.
14. Esposito M, Carotenuto M. Intellectual disabilities and power spectra analysis during sleep: a new perspective on borderline intellectual functioning. *J Intellect Disabil Res*. 2014;58(5):421–429.
15. Esposito M, Carotenuto M. Borderline intellectual functioning and sleep: the role of cyclic alternating pattern. *Neurosci Lett*. 2010;485(2):89–93.
16. Esposito M, Antinolfi L, Gallai B, et al. Executive dysfunction in children affected by obstructive sleep apnea syndrome: an observational study. *Neuropsychiatr Dis Treat*. 2013;9:1087–1094.
17. Shire Pharmaceuticals Limited [webpage on the Internet]. Equasym XL 10 mg, 20 mg or 30 mg capsules. Surrey, UK: Datapharm Communications Limited; 2013. Available from: http://www.medicines.org.uk/emc/medicine/15804/SPC/Equasym+XL+10+mg%2c+20+mg+or+30+mg+Capsules/#CLINICAL_PARTS. Accessed December 15, 2013.
18. Janssen-Cilag Ltd [webpage on the Internet]. Concerta XL 18 mg–36 mg prolonged release tablets. Surrey, UK: Datapharm Communications Limited; 2013. Available from: <http://www.medicines.org.uk/emc/medicine/8382/SPC/Concerta+XL+18+mg+-+36+mg+prolonged+release+tablets/>. Accessed December 12, 2013.
19. Auden Mckenzie (Pharma Division) Limited. *Dexamfetamine Summary of Product Characteristics*. Updated March 23, 2010. <http://www.mhra.gov.uk/home/groups/spcpil/documents/spcpil/con1397196845267.pdf>. Accessed September 1, 2014.
20. Shire Pharmaceuticals Limited [webpage on the Internet]. Elvanse 30 mg, 50 mg and 70 mg capsules, hard. Surrey, UK: Datapharm Communications Limited; 2013. Available from: http://www.medicines.org.uk/emc/medicine/27442/SPC/Elvanse+30mg%2c+50mg+%26+70mg+Capsules%2c+hard/#PHARMACOLOGICAL_PROPS. Accessed October 19, 2013.
21. Eli Lilly and Company Limited. *Strattera. Summary of Product Characteristics*. [Updated December 19, 2013]. <http://www.medicines.org.uk/emc/medicine/14482#INDICATIONS>. Accessed August 28, 2014.
22. Fredriksen M, Halmøy A, Faraone SV, Haavik J. Long-term efficacy and safety of treatment with stimulants and atomoxetine in adult ADHD: a review of controlled and naturalistic studies. *Eur Neuropsychopharmacol*. 2013;23(6):508–527.
23. Faraone SV, Biederman J, Mick E. The age-dependent decline of attention deficit hyperactivity disorder: a meta-analysis of follow-up studies. *Psychol Med*. 2006;36(2):159–165.
24. Vrijens B, De Geest S, Hughes DA, et al; ABC Project Team. A new taxonomy for describing and defining adherence to medications. *Br J Clin Pharmacol*. 2012;73(5):691–705.
25. Horne R, Weinman J, Barber N, et al. *Concordance, Adherence and Compliance in Medicine Taking: Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO)*. London, UK: National Co-ordinating Centre for NHS Service Delivery and Organisation (NCCSDO); 2005.
26. Sabaté E. *Adherence to Long-Term Therapies: Policy for Action*. Geneva, Switzerland: World Health Organization; 2001. Available from: <http://www.who.int/chp/knowledge/publications/adherencerep.pdf>. Accessed April 22, 2014.
27. Bell JS, Airaksinen MS, Lyles A, Chen TF, Aslani P. Concordance is not synonymous with compliance or adherence. *Br J Clin Pharmacol*. 2007;64(5):710–711; author reply 711–713.
28. Aronson JK. Compliance, concordance, adherence. *Br J Clin Pharmacol*. 2007;63(4):383–384.
29. Kravitz RL, Melnikow J. Medical adherence research: time for a change in direction? *Med Care*. 2004;42(3):197–199.
30. Horne R, Weinman J. Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness. *J Psychosom Res*. 1999;47(6):555–567.
31. Adler LD, Nierenberg AA. Review of medication adherence in children and adults with ADHD. *Postgrad Med*. 2010;122(1):184–191.
32. Gau SS, Chen SJ, Chou WJ, et al. National survey of adherence, efficacy, and side effects of methylphenidate in children with attention-deficit/hyperactivity disorder in Taiwan. *J Clin Psychiatry*. 2008;69(1):131–140.
33. Darredeau C, Barrett SP, Jardin B, Pihl RO. Patterns and predictors of medication compliance, diversion, and misuse in adult prescribed methylphenidate users. *Hum Psychopharmacol*. 2007;22(8):529–536.
34. Kooij JJ, Rösler M, Philipsen A, et al. Predictors and impact of non-adherence in adults with attention-deficit/hyperactivity disorder receiving OROS methylphenidate: results from a randomized, placebo-controlled trial. *BMC Psychiatry*. 2013;13:36.
35. Charach A, Yeung E, Volpe T, Goodale T, Dosreis S. Exploring stimulant treatment in ADHD: narratives of young adolescents and their parents. *BMC Psychiatry*. 2014;14:110.
36. Bussing R, Koro-Ljungberg M, Noguchi K, Mason D, Mayerson G, Garvan CW. Willingness to use ADHD treatments: a mixed methods study of perceptions by adolescents, parents, health professionals and teachers. *Soc Sci Med*. 2012;74(1):92–100.
37. Walker-Noack L, Corkum P, Elik N, Fearon I. Youth perceptions of attention-deficit/hyperactivity disorder and barriers to treatment. *Canadian Journal of School Psychology*. 2013;28(2):193–218.
38. Knipp DK. Teens' perceptions about attention deficit/hyperactivity disorder and medications. *J Sch Nurs*. 2006;22(2):120–125.
39. Travell C, Visser J. 'ADHD does bad stuff to you': young people's and parents' experiences and perceptions of attention deficit hyperactivity disorder (ADHD). *Emotional and Behavioural Difficulties*. 2006;11(3):205–216.
40. Wong IC, Asherson P, Bilbow A, et al. Cessation of attention deficit hyperactivity disorder drugs in the young (CADDY) – a pharmacoepidemiological and qualitative study. *Health Technol Assess*. 2009;13(50):iii–iv, ix–xi, 1–120.
41. Brinkman WB, Sherman SN, Zmitrovich AR, et al. In their own words: adolescent views on ADHD and their evolving role managing medication. *Acad Pediatr*. 2012;12(1):53–61.
42. Davis-Berman J, Pestello FG. Medicating for ADD/ADHD: personal and social issues. *Int J Ment Health Addict*. 2010;8:482–492.
43. Pillow DR, Naylor LJ, Malone GP. Beliefs regarding stimulant medication effects among college students with a history of past or current usage. *J Atten Disord*. 2014;18(3):247–257.
44. Meaux JB, Hester C, Smith B, Shoptaw A. Stimulant medications: a trade-off? The lived experience of adolescents with ADHD. *J Spec Pediatr Nurs*. 2006;11(4):214–226.
45. O'Callaghan P. Adherence to stimulants in adult ADHD. *Atten Defic Hyperact Disord*. 2014;6(2):111–120.
46. Matheson L, Asherson P, Wong IC, et al. Adult ADHD patient experiences of impairment, service provision and clinical management in England: a qualitative study. *BMC Health Serv Res*. 2013;13:184.
47. Ferrin M, Ruiz-Veguilla M, Blanc-Betes M, et al. Evaluation of attitudes towards treatment in adolescents with attention deficit hyperactivity disorder (ADHD). *Eur Child Adolesc Psychiatry*. 2012;21(7):387–401.
48. Cox DJ, Davis MT, Cox BS, Burket RC, Merkel RL, Mikami AY. Quantifying the relationship between perceived consequences of ADHD medication and its usage. *J Atten Disord*. Epub 2012 Aug 21.
49. Roy SC, Corliss CP. The Roy Adaptation Model: theoretical update and knowledge for practice. *NLN Publ*. 1993;(15–2548):215–229.

50. Munro S, Lewin S, Swart T, Volmink J. A review of health behaviour theories: how useful are these for developing interventions to promote long-term medication adherence for TB and HIV/AIDS? *BMC Public Health*. 2007;7:104.
51. Charach A, Volpe T, Boydell KM, Gearing RE. A theoretical approach to medication adherence for children and youth with psychiatric disorders. *Harv Rev Psychiatry*. 2008;16(2):126–135.
52. Safren SA, Duran P, Yovel I, Perlman CA, Sprich S. Medication adherence in psychopharmacologically treated adults with ADHD. *J Atten Disord*. 2007;10(3):257–260.
53. Ferrin M, Taylor E. Child and caregiver issues in the treatment of attention deficit-hyperactivity disorder: education, adherence and treatment choice. *Future Neurol*. 2011;6(3):399–413.
54. Harpur RA, Thompson M, Daley D, Abikoff H, Sonuga-Barke EJ. The attention-deficit/hyperactivity disorder medication-related attitudes of patients and their parents. *J Child Adolesc Psychopharmacol*. 2008;18(5):461–473.
55. Caisley H, Müller U. Adherence to medication in adults with attention deficit hyperactivity disorder and pro re nata dosing of psychostimulants: a systematic review. *Eur Psychiatry*. 2012;27(5):343–349.
56. Bussing R, Mehta AS. Stigmatization and self-perception of youth with attention deficit/hyperactivity disorder. *Patient Intell*. 2013;2013(5):15–27.
57. Charach A, Gajaria A. Improving psychostimulant adherence in children with ADHD. *Expert Rev Neurother*. 2008;8(10):1563–1571.
58. Chacko A, Newcorn JH, Feirsen N, Uderman JZ. Improving medication adherence in chronic pediatric health conditions: a focus on ADHD in youth. *Curr Pharm Des*. 2010;16(22):2416–2423.
59. Swanson J. Compliance with stimulants for attention-deficit/hyperactivity disorder: issues and approaches for improvement. *CNS Drugs*. 2003;17(2):117–131.
60. Young S, Murphy CM, Coghill D. Avoiding the ‘twilight zone’: recommendations for the transition of services from adolescence to adulthood for young people with ADHD. *BMC Psychiatry*. 2011;11:174.

Patient Preference and Adherence

Publish your work in this journal

Patient Preference and Adherence is an international, peer-reviewed, open access journal that focuses on the growing importance of patient preference and adherence throughout the therapeutic continuum. Patient satisfaction, acceptability, quality of life, compliance, persistence and their role in developing new therapeutic modalities and compounds to optimize

Submit your manuscript here: <http://www.dovepress.com/patient-preference-and-adherence-journal>

clinical outcomes for existing disease states are major areas of interest for the journal. This journal has been accepted for indexing on PubMed Central. The manuscript management system is completely online and includes a very quick and fair peer-review system, which is all easy to use. Visit <http://www.dovepress.com/testimonials.php> to read real quotes from published authors.

Dovepress