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ORIGINAL ARTICLE

Barriers to evidence-based treatment for children with attention-deficit/hyperactivity disorder

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Abstract A number of evidence-based treatments are available for attention-deficit/hyperactivity disorder (ADHD), including pharmacological, psychosocial, or a combination of the two treatments. For a significant number of children diagnosed with ADHD, however, these treatments are not utilized or adhered to for the recommended time period. Given that adherence to treatment regimens is necessary for reducing the symptoms of ADHD, it is crucial to develop a comprehensive understanding of why adherence rates are so low. The current review examines the literature to date that has directly explored utilization and adherence issues related to the treatment of ADHD in order to identify the key barriers to treatment. This review focused on four main factors that could account for the poor rates of treatment utilization and adherence: personal characteristics (socio-demographic characteristics and diagnostic issues), structural barriers, barriers related to the perception of ADHD, and barriers related to perceptions of treatment for ADHD. This review included 63 papers and covered a variety of barriers to treatment that have been found in research to have an impact on treatment adherence. Based on this review, we conclude that there are complex and interactive relationships among a variety of factors that influence treatment utilization and adherence. Four main gaps in the literature were identified: (1) there is limited information about barriers to psychosocial interventions, compared to pharmacological interventions; (2) there is a limited variety of research methodology being utilized; (3) treatment barrier knowledge is mostly from parents' perspectives; and (4) treatment utilization and treatment adherence are often studied jointly. Information from this review can help practitioners to identify potential barriers to their clients being adherent to treatment recommendations.

Keywords Treatment · Barriers · ADHD · Treatment adherence · Treatment utilization · Perceptions

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Introduction

Attention-deficit/hyperactivity disorder (ADHD) is a chronic and complex mental health disorder characterized by developmentally inappropriate levels of inattention, hyperactivity, and impulsivity (American Psychiatric Association [APA] 2013). Recent large-scale epidemiological studies in the USA have estimated the prevalence of ADHD at 5 % in school-aged children (APA 2013), and as such, ADHD is one of the most common diagnoses provided to children at outpatient mental health services (Staller 2006). ADHD is also associated with serious

behavioural, academic, and social difficulties, which often persist into adolescence and adulthood (Schachar 2009).

A significant body of research exists to support the idea that the symptoms of ADHD and associated impairments in social, occupational, or academic functioning can be successfully reduced using: (1) medication (e.g. methylphenidate, dextroamphetamine, or atomoxetine), (2) behaviour modification (e.g. parent training, classroom contingency management), and (3) a combination of the two (Kaiser and Pfiffner 2011; Vaughan et al. 2012). Psychostimulant medications are the pharmacological treatment most often prescribed for ADHD (Swanson 2003) and have been shown to significantly reduce the core symptoms of ADHD (e.g. MTA Cooperative Group 2004). Less research has examined the impact of psychosocial interventions, which include a variety of strategies such as reward systems, social skills training, and behavioural interventions; however, these treatments have also been shown to have beneficial effects for children with ADHD (Kaiser and Pfiffner 2011).

Debate continues in the literature as to the relative benefits of medication, psychosocial intervention, and a combination of these two treatments. Results from the 14-month time point in the largest trial ever conducted on treatments of ADHD in elementary-aged children (MTA Cooperative Group 1999) found that combined treatment (i.e. medication and psychosocial intervention together) and medication management did not differ significantly in terms of their impact on the majority of ADHD symptoms. Moreover, combined treatment and medication management proved more effective than a psychosocial intervention or regular community care. Combined treatment was superior to medication management for some associated symptoms, but not core ADHD symptoms. More recently, researchers have described combined treatment (i.e. medication and behavioural management) as *necessary* (Chronis et al. 2006) and as the *gold standard* (Daly et al. 2007) in the treatment of children with ADHD. The International Consensus Statement on attention-deficit/hyperactivity disorder (ADHD) and disruptive behaviour disorders (DBDs; Kutcher et al. 2004) and the Practice Parameter for the Assessment and Treatment of Children and Adolescents with ADHD (American Academy of Child and Adolescent Psychiatry 2007) have also recognized the importance of both forms of treatment for ADHD.

What we can definitely conclude from research is that highly effective treatments for ADHD have been developed. Unfortunately, research conducted around the world has also determined that ADHD is undertreated (Cuffe et al. 2009; Ford et al. 2008; Vanheusden et al. 2008). A large epidemiological study of children in the USA who were diagnosed with ADHD found that over a 1-year period, only about 12 % were treated with medication and only 30 % had received some sort of psychosocial intervention (Jensen et al. 1999). Similar rates have been found in Australia, with 28 % of children with ADHD receiving some sort of service in the past 6 months and 18.3 % taking a type of medication (Sawyer et al. 2004). Jensen et al. (1999) concluded that in the USA, only 46 % of children with ADHD who needed medication, 32 % of children with ADHD who needed counselling, and 26.5 % of families who needed help with their child's behaviour problems had received the intervention they needed.

Lack of treatment is in part related to the fact that families and children do not always act on treatment recommendations. Overall, treatment initiation rates of approximately 65 % are commonly reported (e.g. Brown et al. 1987; MacNaughton and Rodrigue 2001) with families being somewhat more likely to pursue recommendations for medication than for psychological or counselling interventions (Bennett et al. 1996; MacNaughton and Rodrigue 2001). It is important to note, however, that beginning treatment does not necessarily mean that families and children continue with treatment. Studies have found that approximately 25 % of children and families discontinued treatment with stimulant medication over a 1-year period (Corkum et al. 1999; Faraone et al. 2007). Over a 5-year period, Charach et al. (2004) found that adherence rates declined even further, to 53 % of children adhering after 2 years and to 36 % adhering after 5 years. Even in the short term (i.e. over a 4-week period), research has shown that only about 40 % of children take every dose of medication prescribed (Gau et al. 2006).

In a review of psychosocial treatments for ADHD, Pelham et al. (1998) reported that only a small number of behaviour intervention studies actually measured adherence to treatment, making definitive adherence estimates (and the determination of treatment fidelity) difficult. Two studies that did measure adherence to parent training programs reported very similar rates. In a Canadian study, Corkum et al. (1999) found that over the 12 months of their study, 57.7 % of families attended more than half of the parent sessions. A parent training study in Taiwan (Huang et al. 2003) found that 14 of the 23 families (61 %) completed a 10-week program. Low levels of treatment adherence are not unique to the field of ADHD, but are an issue in paediatric medicine in general. For example, adherence to medication treatments for cystic fibrosis has been found to be approximately 64 % (Zindani et al. 2006), while adherence to dietary recommendations associated with medical treatments is often under 50 % (Mackner et al. 2001).

The wide-spread under-treatment of ADHD seems then to be due to a combination of children and families not beginning treatment at all and the lack of adherence to recommended treatments. Given that ADHD symptoms are associated with significant, long-term behavioural, academic, and interpersonal challenges and that effective treatments are

available but under-utilized, it is crucial that we develop a comprehensive understanding of the barriers preventing children and families from beginning and/or adhering to treatment.

Owens et al. (2002) examined barriers to the delivery of children's mental health services in general. They identified three broad categories including: (1) structural barriers (e.g. long waiting lists or cost); (2) barriers related to perceptions about mental health problems (e.g. denial of the severity of the problem); and (3) barriers related to perceptions about mental health treatment services (e.g. lack of confidence in professionals or stigma related to receiving treatment). They also found that psychosocial characteristics of the family and children were related to the number of reported barriers. Despite the fact that ADHD is one of the most commonly researched disorders in children and adolescents, surprisingly little research has examined the barriers to treatment for children and families coping with this disorder. As a result, little is known about the specific barriers that are preventing families of children with ADHD from initiating or continuing with recommended treatments for this disorder. The goal of this review was to systematically examine and summarize this body of literature. This review is structured around the three broad categories reported above (i.e. based on the categories put forth by Owens et al. 2002) and will also examine socio-demographic factors and factors related specifically to the diagnosis of ADHD. We also created themes within each category based on a qualitative review and grouped information into these themes as subcategories.

Methods

A review of the literature was conducted using three databases: (1) PsycINFO (www.apa.org/psycinfo), (2) PubMED (www.pubmed.gov), and (3) ERIC (www.eric.ed.gov). For the database search, the term ADHD was paired with each of the following terms: treatment, adherence, compliance, barrier, utiliz*, media, and behaviour. Table 1 provides an overview of the studies identified that met the following criteria: (1) a stated goal of the research study to evaluate factors related to ADHD treatment utilization and adherence, (2) a publication date of 1987 (corresponding to the publication of the DSM-III-R; APA 1987) or later, and (3) publication in a peer-reviewed journal. Case studies, literature reviews, book chapters, student theses, and studies in languages other than English were excluded from the review. It is important to note that articles that only reported adherence rates as part of a larger study were not included. However, several articles that did not meet the review inclusion criteria are cited throughout the text to provide an overall context for the findings.

Results and discussion

After the review of the literature, 63 studies were found that met our inclusion/exclusion criteria; these can be found in Table 1. As mentioned above, several articles that did not meet criteria are included in order to provide relevant context. These articles are clearly indicated in footnotes. The findings in this review have been divided into four main sections. The first section, personal characteristics, includes a discussion of the relationships among socio-demographic factors and ADHD treatment utilization and adherence, as well as a review of the diagnostic issues that are potentially related to treatment barriers. The next three sections are organized according to the categories of barriers to child mental health treatment identified by Owens et al. (2002): structural barriers, barriers related to perceptions of ADHD, and barriers related to perceptions of treatment for ADHD. See Fig. 1 for a graphical representation.

1. Personal characteristics (i.e. socio-demographic and diagnostic)

Most of the research that has studied factors related to treatment utilization and adherence in children with ADHD has focused on socio-demographic and diagnostic factors. Of the 63 articles reviewed, 30 of the studies cited socio-demographic and diagnostic barriers to treatment. Studies examining pharmacological, psychosocial, and combination treatments were reviewed. The following variables have all been shown to be related to diagnostic and treatment patterns for ADHD: (i) sex, (ii) age of the child, (iii) ethnicity, (iv) socio-economic status (SES), and (v) comorbid diagnoses. Each of these will be discussed below. Other barriers identified in this category were being from a single-parent home (Bird et al. 2008) and negative family influences (e.g. parental stress, parental psychopathology, etc.; Schneider et al. 2013). These types of barriers were not as often identified as the five identified above.

(i) *Sex* It is estimated that the ratio of diagnosis of ADHD is approximately four males to every female (APA 2000), although some researchers believe that ADHD in females may be underdiagnosed. Among those children diagnosed with ADHD, boys have been found to be more likely to receive treatment (Barbaresi et al. 2006; Bussing et al. 1998). In terms of help-seeking, one study found that parents of boys with ADHD reported taking more help-seeking steps (e.g. speaking to someone about ADHD) than parents of girls with ADHD (Bussing et al. 2005).

Table 1 Sixty-three studies included in review of factors associated with adherence to treatments for ADHD

Study citation	Study design/methods	Sample characteristics	Factors associated with adherence to treatments for ADHD			
			Personal characteristics (socio-demographic and diagnostic)	Structural barriers	Perception of ADHD	Perception of treatment
Ahmed et al. (2013a, b)	Focus groups with parents of children with ADHD	16 parents of children with ADHD from the metropolitan Sydney area. Their child had to be taking stimulant medication or had been taking it in the previous 6 months			Experiencing stigma from a number of sources (i.e. beliefs of other parents that ADHD is not real, and that it does not require drugs to be controlled) was a barrier to beginning treatment	The positive impact of medication on the child's behaviour was the key factor influencing the decision to continue with medication. Side effects of medication were one of the major concerns, which often led to treatment cessation; parents also expressed concern about the long-term effects (i.e. addiction, abuse)
Angold et al. (1998)	Adolescents and parents completed structured interviews. Parents completed the Child and Adolescent Burden Assessment	1,015 9-, 11-, and 13-year-olds and their parents			Parental perception of children's behaviour can influence the decision to pursue treatment	
Arcia et al. (2004)	Interviews	62 Latina mothers of children aged 4–10 years with symptoms of ADHD, ODD, or CD	Latina mothers had concerns about stimulant medications, such as belief of serious side effects or addiction to medication			Medication is not a desirable treatment. The possibility of being prescribed medication can be a barrier to seeking treatment
Arnold et al. (2003)	Subanalysis of MTA data; matched African American and Latino participants with Caucasian participant of same gender, treatment group, and site	258 children with ADHD; 92 African American matched with 92 Caucasian; 37 Latino matched with 37 Caucasian	No significant differences between groups regarding adherence to medication or attendance at behavioural sessions			
Atzori et al. (2009)	A group of children diagnosed with ADHD were assessed monthly for 36 months, and medication outcomes were assessed (continuing medication, medication withdrawn due to functional remission, or medication withdrawn for other reasons including poor compliance)	134 children between the ages of 4 and 16, mean age = 9 ± 2 years; 84 % combined subtype	Older age and hyperactive subtype were predictive of withdrawing medication for other reasons including poor compliance			

Table 1 continued

Study citation	Study design/methods	Sample characteristics	Factors associated with adherence to treatments for ADHD			
			Personal characteristics (socio-demographic and diagnostic)	Structural barriers	Perception of ADHD	Perception of treatment
Bailey and Owens (2005)	Online or telephone surveys were conducted in households with at least one member between the ages of 6 and 17 to identify barriers to ADHD treatment from May to July 2002	1,074 African American respondents and 1,238 Caucasian respondents			The stigma of ADHD and lack of information about ADHD were significant barriers to treatment among African American respondents	
Barbaresi et al. (2006)	Retrospective study examining stimulant medication treatment	379 children with research-identified ADHD in the 1976–1982 Rochester, MN birth cohort	Boys were 1.8 times more likely than girls to be treated. Median age at initiation of treatment, median duration of treatment, and likelihood of developing at least one side effect were not significantly different by gender			
Barner et al. (2011)	Individual patient claims were drawn from the Texas Medicaid database, from the time period of 1 July 2002–31 December 2008	62,789 children between the ages of 3 and 18 from the Texas Medicaid database. Mean age was 8.5 ± 3.5 years, 69.2 % male	Adolescents were less likely to adhere to medication than preschoolers; females were more likely to adhere than males	Non-stimulants and extended-release stimulants had the highest adherence rates, versus immediate-release stimulants		
Beck et al. (2005)	Children with ADHD or autistic disorder participated in behavioural training to increase cooperation with pill swallowing	8 children with ADHD or autistic disorder aged 4–9 years old		Difficulty swallowing pills is a medication barrier in the paediatric population		
Bennett et al. (1996)	Measured knowledge of ADHD and opinions about ADHD treatments, prior to initial clinic visit and 4 months later	150 parents of 91 children referred to an ADHD clinic for assessment; 76 males; aged 5–3 Follow-up: only able to contact 49 families		No relationship between ratings of counselling feasibility and adherence at 4 months	Increased parental knowledge about ADHD associated with higher levels of medication acceptability	Found no relationship between acceptability of counselling or medication and adherence to medication at 4 months

Table 1 continued

Study citation	Study design/methods	Sample characteristics	Factors associated with adherence to treatments for ADHD			
			Personal characteristics (socio-demographic and diagnostic)	Structural barriers	Perception of ADHD	Perception of treatment
Berger-Jenkins et al. (2012)	A convenience sample of parents were approached in the waiting room of either paediatric primary care or mental health specialty care clinics from July 2005–July 2006, and were asked to complete a survey assessing predictors of ADHD service utilization	70 parents of children with ADHD, aged 5–17			(mean = 8.9 ± 3.2 years), predominantly from a low-income, Hispanic and African American population	Increasing age was associated with less follow-up at mental health appointments and less utilization of treatments
		Medication concerns were associated with less follow-up at mental health appointments and less utilization of treatments				
Bird et al. (2008)	Longitudinal data were obtained on Puerto Rican children from the South Bronx and Puerto Rico, to collect information about risk factors for low treatment use	1,138 Puerto Rican children from the South Bronx, and 1,353 children from Puerto Rico, aged 5–13 years	Negative family influences were predictive of lower rates of treatment, and low maternal acceptance/warmth was predictive of higher rates of treatment			Caregivers' attitude towards medication treatment had more of a bearing on treatment seeking than did the psychiatric needs of the child
Brinkman et al. (2009)	Qualitative study, using parental focus groups, to examine decision-making, information-sharing, and sources of conflict and uncertainty surrounding the decision to treat their child's ADHD	52 parents with children between the ages of 6 and 17 who had been diagnosed with ADHD (75 % white, 25 % black). 60 % of children were male		Lack of physician support and/or trust, poor communication with teacher, and lack of support from relatives were identified as factors that delayed the initiation of medication	Parent denial that their child has a problem, lack of confidence in diagnosis, and stigma were identified as delaying initiation of stimulant treatment	Story or experience that opposes treatment with medication, other information sources that oppose treatment with medication, general reluctance to use medication, parent concerns about relying on medication to fix things, drug addiction, and medication side effects were factors that delayed treatment initiation

Table 1 continued

Study citation	Study design/methods	Sample characteristics	Factors associated with adherence to treatments for ADHD			
			Personal characteristics (socio-demographic and diagnostic)	Structural barriers	Perception of ADHD	Perception of treatment
Brown et al. (1987)	Adherence to a 3-month protocol (a combination of methylphenidate or placebo and cognitive therapy, or an attention-control procedure) was measured	58 children (47 male and 11 female), aged 6–13 years diagnosed as having serious and persistent symptoms associated with ADD (only about 1/2 of these subjects completed the study)	Minority children missed more medication and failed to attend more therapy sessions than Caucasian children. Fewer sessions were missed when the child's biological parents were still married. The lower the child's IQ score, the greater the number of pills missed			
Brownell et al. (2006)	Methylphenidate use in cycle 2 of the National Longitudinal Survey of Children and Youth was recorded	11,316 children, 2–11 years, from cycle 1 (1994–1995) of the National Longitudinal Survey of Children and Youth were followed up 2 years later in cycle 2	Children with lower SES were more likely to use methylphenidate. As SES increased, methylphenidate use decreased. Boys were almost 3 times more likely than girls to take methylphenidate		Strongest predictor of the incidence of methylphenidate use was hyperactive-impulsive and inattentive behaviours	
Bussing et al. (1998)	Interviews with parents and children	143 parents of children who have ADHD and who attend special education classes	Female gender, minority status, and rural residence were associated with lower levels of ADHD service use			
Bussing et al. (2003a)	Parental responses to ethnographic interviews	182 elementary school-aged children with ADHD	Fewer African American parents rated medication as favourable versus Caucasian parents (70 vs. 79 %)			25 % of parents felt that medication was probably not appropriate or not appropriate
Bussing et al. (2003b)	Parental interviews and questionnaires	389 children at high risk for ADHD; 52 % male; 48 % Caucasian; 52 % African American; mean age = 7.8 years	Males and Caucasians more likely to be evaluated, diagnosed, and treated for ADHD; higher SES predicted treatment utilization	Unsure where to go for help (53 %) Financial limitations (38 %)		Expected treatment would not help (45 %) Perceived stigma (39 %)
Bussing et al. (2005)	Qualitative information from parents and information extracted from school database	Parents of 259 children with ADHD or identified as high risk for ADHD; 126 male; 174 Caucasian; mean age = 9.6 years	Parents' interpretation of symptoms and choice of treatment was related to gender and race of the child. Caucasian males received the most help			

Table 1 continued

Study citation	Study design/methods	Sample characteristics	Factors associated with adherence to treatments for ADHD			
			Personal characteristics (socio-demographic and diagnostic)	Structural barriers	Perception of ADHD	Perception of treatment
Bussing et al. (2007)	Structured 20- to 30-min telephone interviews	A representative community sample of 1,615 parents	Less ADHD awareness and lower self-rated knowledge was reported by African American parents. They also reported fewer "cues to action" (i.e. receiving information about ADHD from their child's teacher)		African American parents attributed more causation to sugar intake	African American parents expected less benefit from treatment, than did Caucasian parents
Chan et al. (2002)	The 1996 Medical Expenditure Panel Survey, a nationally representative household survey	5,439 children aged 5–20 years old from the 1996 Medical Expenditure Panel Survey		Overall costs of care for children with ADHD were compared to costs for children with Asthma and were found to be significantly higher than the general population		
Charach et al. (2004)	Adherence to stimulant treatment and adverse effects were evaluated annually for 5 years	79 children who enrolled in a follow-up study after completing a 12-month randomized control trial (combined methylphenidate and parent training programs)			Adherents tended to be children who had more severe symptoms at baseline	
Coletti et al. (2012)	Parents of children with ADHD who were given a stimulant treatment recommendation participated in focus groups to identify facilitators and barriers of seeking stimulant medication	27 parents, mean child			age = 9.35 ± 2.00 years. 81.5 % of parents had pursued stimulant treatment	
		Fears about negative side effects and about personality changes were identified as barriers to treatment adherence				
Corkum et al. (1999)	Measured parental knowledge and opinions about ADHD and treatment prior to being randomized in a 12-month treatment study	Parents of 81 children with ADHD; 70 males and 11 females; aged 5–12 years			Higher knowledge of ADHD associated with more favourable opinions of psychosocial treatments	Parents' ratings of medication acceptability were predictive of pursuit of treatments for ADHD but not to adherence rates

Table 1 continued

Study citation	Study design/methods	Sample characteristics	Factors associated with adherence to treatments for ADHD			
			Personal characteristics (socio-demographic and diagnostic)	Structural barriers	Perception of ADHD	Perception of treatment
Cormier (2012)	Grounded theory-guided data collection and analysis, and semi-structured interviews	16 parents (13 mothers, 3 fathers) of children with ADHD (6 girls, 10 boys; age = 6–11 years)		Parents' feeling responsible for managing their child's behaviour without medication and feeling blamed for their child's behaviour delayed initiation of medication. Parents also identified frustration and dissatisfaction with the guidance they received as a barrier	Parents delayed initiation of medication, hoping that their child would grow out of the ADHD symptoms or that another intervention would be successful	Resisting medication was related to misgivings due to uncertainty, negative stigma, and concerns about side effects
Davis et al. (2012)	Qualitative interviews	28 families with children with ADHD, aged 6–15 years (79 % male). 22 families were using medication for their child's ADHD, 19 families reported having used behaviour modification, 20 using school-based interventions, and 12 using non evidence-based interventions		When clinicians were more forceful about their perspective on effective treatment approaches, families were less likely to adopt their recommendations. Families also identified insurance issues, access to school and medical services, and driving frequently to doctors' offices as barriers	Parents who believed their child's behaviour was caused by poor parenting or lack of discipline initially rejected medication, as it was not in line with their view of the causes of the disorder	Beliefs that psychotropic medication is not appropriate for children, concerns about side effects (weight loss, "zombie"-like behaviour), and fear of future addiction problems were identified as reasons for initially rejecting medication
dosReis et al. (2003)	Survey to determine parental perception and satisfaction with stimulant medication for ADHD	302 parents recruited from 6 paediatric primary care clinics	Minority families were less likely to prefer medication over counselling, less satisfied with medication, and more likely to believe medication for ADHD is associated with negative side effects			Families viewed medication as an unattractive treatment option
dosReis et al. (2006)	Parental attitudes about the risks and benefits of stimulant treatment via a survey	57 African American parents in a paediatric primary care clinic of children aged 19 years old or younger, who had been taking stimulant medications in the past 12 months				Participants expressed concerns about the potential for medication to lead to drug abuse and to have negative side effects and expressed a preference for counselling over medication treatment

Table 1 continued

Study citation	Study design/methods	Sample characteristics	Factors associated with adherence to treatments for ADHD			
			Personal characteristics (socio-demographic and diagnostic)	Structural barriers	Perception of ADHD	Perception of treatment
Dreyer et al. (2010)	Parents of children referred to an ADHD clinic completed a telephone interview 4–6 weeks after receiving evaluation feedback	80 parents or caregivers, ranging in age from 23 to 59 years (mean age = 34.94 ± 7.16 years), 88 % female, 95 % Caucasian		Lack of time (38.8 %) Lack of teacher cooperation (37.5 %) Resources not available in community (28.8 %) Waiting for appointment (18.8 %) Lack of insurance coverage (8.8 %)		Wanted to try behavioural interventions before medication (23.8 %) Did not think it would help (13.8 %)
Gage and Wilson (2000)	Parental questionnaires	30 (19 female, 11 male) parents of children with ADHD and 30 (19 female, 11 male) parents of children without ADHD				Parents of children with ADHD appear to rate medication and combination treatment scenarios as more acceptable than parents of children without ADHD
Gau et al. (2006)	Questionnaires were completed assessing demographic information, adherence, and family dynamics	307 children with ADHD (271 boys, 36 girls); 6–17 years old; treated with immediate-release methylphenidate for previous 6 months		Methylphenidate taken multiple times a day decreases adherence, especially in adolescents		
Gau et al. (2008)	Children with a diagnosis of ADHD and their parents were interviewed and completed a series of questionnaires to determine information about adherence and other variables	607 children, 83 % male	Older age, later age at ADHD diagnosis, positive family history of ADHD (especially father), and paternal education of college or higher were determinants of poor treatment adherence	Administration of methylphenidate twice or thrice daily, and higher mean dose were determinants of poor adherence		
Graetz et al. (2006)	Interviewed parents about service use (e.g. family physician, paediatrician, counselling at school) in the past 6 months	398 children with ADHD (279 males); aged 6–17 years	Proportionally more males attended services for ADHD than females. Males with more symptoms and earlier onset, and older females, had greater service use			
Guevara et al. (2001)	Retrospective matched cohort study	Children 3–17 years, who were continuously enrolled in the HMO from 01 January to 31 December 1997 and who made at least one ambulatory visit or hospitalization		Children with ADHD incurred significantly greater per capita total costs than children without ADHD		

Table 1 continued

Study citation	Study design/methods	Sample characteristics	Factors associated with adherence to treatments for ADHD			
			Personal characteristics (socio-demographic and diagnostic)	Structural barriers	Perception of ADHD	Perception of treatment
Hong et al. (2013)	Observational study, surveying newly diagnosed ADHD patients in East Asia and Central Europe	860 children aged 6–17 years	Being from East Asia was a strong predictor of non-adherence. Family history of ADHD and parental distress were predictive of non-adherence in East Asia, while being an only child was predictive of non-adherence in Central Europe, as well as overall			
Kelleher et al. (2001)	Insurance claims data from Medicaid agency	Eligibility and claims records for publicly insured children from the Pennsylvania State DPW for 7 counties during 1994–1995		Pharmaceutical costs were 42 % higher for children with ADHD than for those with a similarly prevalent comparison condition (asthma)		
Krain et al. (2005)	Questionnaires completed before treatment and 4 months later	55 parents of children with ADHD aged 5–12 years; gender: 65.5 % male; ethnicity: 74.5 % Caucasian	Caucasians more likely to rate medication as acceptable and are more likely to pursue it			Behaviour therapy rated more acceptable than medication. After controlling for race, parent acceptability ratings predicted pursuit of treatment for medication
Leibson et al. (2001)	Population-based cohort study	Children born in 1976–1982 from Rochester, MN, were followed through 1995 ($n = 4{,}119$), using school/medical records to identify those with ADHD		Children with ADHD used substantially more medical care than children without ADHD		
Liu et al. (1991)	Acceptability of methylphenidate, behaviour modification, and a combination of the two were evaluated prior to ADHD intervention and reassessed 3.5 months after ADHD intervention	50 mothers of children with ADHD, 50 control mothers, 21 children with ADHD, and 20 control children			Mothers' knowledge of ADHD was significantly, positively correlated with their acceptance of methylphenidate for treating ADHD	All families rated behaviour modification as most acceptable and methylphenidate as least acceptable. At follow-up, they found a significant improvement in the acceptability of methylphenidate and the combined condition. This increased acceptability was related to increased parental knowledge of ADHD

Table 1 continued

Study citation	Study design/methods	Sample characteristics	Factors associated with adherence to treatments for ADHD			
			Personal characteristics (socio-demographic and diagnostic)	Structural barriers	Perception of ADHD	Perception of treatment
Maniadaki et al. (2006)	Compared belief of severity, impact, and advice-seeking of parents of children presenting ADHD behaviours with parents whose children do not display such behaviours via questionnaires	590 parents (295 mothers and 295 fathers) of children, aged 4–6, enrolled in kindergartens and nursery schools			Parents reporting ADHD behaviours in their child perceived the behaviours as less severe, and with less negative impact than parents who did not report such behaviours. However, the more severe ADHD behaviours are perceived to be and the more impact these behaviours are considered to have on the child, the more likely it is that parents would seek a specialist's advice	
Marcus et al. (2005)	Compared adherence to medication between children taking immediate-release and extended-release stimulant medication	8,093 prescribed immediate-release form; 78.2 % male 3,444 prescribed extended-release form; 77.5 % male aged 6–17 years		Children prescribed the extended-release form continued treatment for 37 % longer than children prescribed the immediate-release form		
Miller et al. (2004)	Retrospective longitudinal database analytic study from health and prescription data from the entire population of British Columbia	18,081 children who had been prescribed methylphenidate between 1 January 1990 and 31 December 1996. Average age of first prescription was 9.6 years. 4.4:1 male:female ratio	Therapy bout lengths decreased as patient age increased. Males received more therapy bouts than girls			
Miltenberger et al. (1989)	Assessed the acceptability of alternative psychosocial treatments	97 parents or grandparents at a clinic for children with behavioural disorders				Psychosocial treatments were rated as more acceptable than pharmacological
Monastra (2005)	Parents completed a survey	856 families with a child with ADHD who were not adherent to treatment; aged 6–20 years; gender: 80 % male			Concerned that there was no direct test of attention (90 %) Lack of knowledge about ADHD (22 %)	Fear of side effects (92 %). Continued problems despite medication (49 %) Side effects (48 %) Lack of knowledge about medication (30 %)
Ohan and Johnston (2000)	Medication adherence data were collected twice, 2 months apart, as reported by parents and adolescents	44 adolescents who were prescribed medication for ADHD and one parent	Parents and adolescents reported high rates of adherence to stimulant medication			

Table 1 continued

Study citation	Study design/methods	Sample characteristics	Factors associated with adherence to treatments for ADHD			
			Personal characteristics (socio-demographic and diagnostic)	Structural barriers	Perception of ADHD	Perception of treatment
Owens et al. (2002)	At each time point (first grade-fall and spring, sixth grade-spring, seventh grade-spring), children, parents, and teachers were interviewed	799 children enrolled in 27 classrooms were recruited. Analysis was restricted to 116 families based on indication of need for service		35 % of parents reported a barrier, such as structural constraints, perceptions of mental health, and perceptions of services	The way a parent perceives the behaviour of his or her child can influence the decision to pursue and adhere to treatment	
Palli et al. (2012)	Retrospective longitudinal claims analysis of 3 years of data from Medicaid Analytic extract data (January 2003–December 2005)	46,135 children with ADHD between the ages of 6 and 19, mean age = 9.2 years	Black and Hispanic children had lower persistence rates than other children in the study, while foster care was positively related to persistence			
Power et al. (1995)	Elementary and middle school teachers read vignettes and rated the acceptability of psychosocial and pharmacological interventions for ADHD	147 elementary and middle school teachers from four school districts				Daily report was significantly more acceptable than response cost and medication. Also, medication was rated as more acceptable when used in conjunction with psychosocial interventions than when used in isolation
Ray et al. (2006)	Estimated healthcare service costs for children 2 years before diagnosis of ADHD and 2 years after. Costs were compared with those for children without ADHD	3,122 children without and 15,899 children with ADHD (aged 2–10 years)	Children diagnosed with ADHD use more health services than children without ADHD. Among those diagnosed children, minority Americans use less services than Caucasian Americans			

Table 1 continued

Study citation	Study design/methods	Sample characteristics	Factors associated with adherence to treatments for ADHD			
			Personal characteristics (socio-demographic and diagnostic)	Structural barriers	Perception of ADHD	Perception of treatment
Reimers et al. (1992)	Parental acceptability ratings of recommended positive reinforcement procedures were obtained at initial clinic visit and 1, 3, and 6 months later	50 families seeking services for their children in a behaviour management outpatient clinic				Higher acceptability rating was correlated with compliance to treatment Positive treatment approaches are more acceptable than reductive approaches More expensive treatments may be less acceptable Potential side effects may have an impact on acceptability ratings Effective treatments are more acceptable Treatment integrity can impact treatment effectiveness, which can thereby affect acceptability ratings Understanding of the treatment may affect acceptability ratings
Rieppi et al. (2002)	Subanalysis of MTA data; examined relationships between a variety of SES variables and adherence to treatment	579 children with ADHD; aged 7–9 years	Higher rates of adherence to psychosocial and combination treatments related to higher parental education levels, income, job status, and two-parent families. Medication adherence not related to SES variables			
Rothenberger et al. (2011)	Children who were prescribed methylphenidate (either once-daily, immediate-release; multiple dosings; or Equasym XL, a modified release form) by their regular physician were included in the study. Questionnaires were completed by physicians, parents, and children	822 patients aged 6–17 years (81 % male)		Adherence was rated as better for Equasym XL than for alternative forms of methylphenidate		

Table 1 continued

Study citation	Study design/methods	Sample characteristics	Factors associated with adherence to treatments for ADHD			
			Personal characteristics (socio-demographic and diagnostic)	Structural barriers	Perception of ADHD	Perception of treatment
Sawyer et al. (2004)	Parental questionnaires	398 children with ADHD (279 males), aged 6–17 years (same sample as Graetz et al. 2006, above)		Cost of services (14.7 %) Not knowing where to get help (14 %) Length of waiting lists (10.5 %)	Attitudes of friends and family (2.8 %)	Felt they could manage child's behaviour on own (20.3 %)
Sayal et al. (2003)	Interviews and questionnaires examined predictors of parental perception of hyperactivity as a serious problem and its role in the use of specialist services	Community sample of 5- to 11-year-old children who displayed pervasive hyperactivity ($n = 93$)			Mental health service use is increased when the impact of hyperactivity on parents' work and family finances is substantial	
Sayal et al. (2006)	Parental questionnaires	232 children with ADHD; age: 5–15; gender: 81 % male			Parental opinions of symptoms and impact of symptoms are related to help-seeking; parents are not discussing their concerns with their primary healthcare providers	
Schneider et al. (2013)	Children underwent a comprehensive ADHD assessment before completing treatment. Variables related to treatment dropout and adherence were measured	73 families who attended a university-based ADHD clinic for treatment of their child's ADHD. 57 families completed the initial assessment, and 35 families completed treatment	Severity of conduct disorder (CD), oppositional defiant disorder (ODD), and hyperactive/impulsive symptoms; not being on medication for ADHD; being from a single-parent home; and ethnic minority status were all related to higher rates of assessment or treatment dropout			

Table 1 continued

Study citation	Study design/methods	Sample characteristics	Factors associated with adherence to treatments for ADHD			
			Personal characteristics (socio-demographic and diagnostic)	Structural barriers	Perception of ADHD	Perception of treatment
Sitholey et al. (2011)	Children and adolescents newly diagnosed with ADHD were followed and assessed for adherence and factors affecting adherence rates	24 Indian children (21 male, 3 female), mean age = 8.5 ± 2.6 years. 20 children had comorbid conditions; 19 were on methylphenidate and 5 on clonidine	Comorbid mental retardation was negatively correlated to adherence, while higher baseline severity of ADHD was predictive of adherence	Problems in hospital, like long waiting time (50 %) Problems in access to treatment (40 %) High cost of medication (40 %) Child refusing to take medication (30 %) Multiple doses of medication (15 %) Other medical practitioners opposing the use of medication (15 %)	Notion that disorder will subside on its own (30 %) ADHD not being the primary concern for treatment (10 %)	Side effects of medication (65 %) Lack of perceived effectiveness of medication (50 %) Fear that the child will become addicted to medication (45 %) Careless attitude of caregivers (40 %) Family members other than parents opposing the medication (30 %) Long duration of treatment (30 %) Fear of side effects (20 %)
Stevens et al. (2005)	Data were utilized from the 1997 to 2000 Medical Expenditure Panel Survey (MEPS) to assess various stages of ADHD healthcare	27,802 observations from children between the ages of 3 and 18 were included, with 1,061 children with ADHD	Caucasian children were more likely to receive a prescription for a stimulant medication than were African American children. Older children were also more likely than younger children	Children with private insurance were more likely to receive a prescription for stimulant medication than children with public insurance or no insurance. Children with public insurance had more psychotherapy visits for ADHD than children with private or no insurance		
Swensen et al. (2003)	Administrative database, including all medical, pharmaceutical, and disability claims from beneficiaries of a national, Fortune 100 manufacturer	1,025 ADHD cases were matched to 1,086 control cases by age, gender, state of residence, and employment status to controls		Children with ADHD as well as their parents and siblings, were more likely to have increased medical costs		
Tarnowski et al. (1992)	Case description methodology	80 mothers (40 African American, 40 Caucasian); children seen for routine paediatric outpatient care at a large urban hospital	Treatment acceptability did not vary as a function of subject race or socio-economic status		Severity of externalizing behavioural symptomology failed to significantly influence acceptability ratings	Pharmacologic intervention was the least preferred treatment Only psychosocial treatments, either in isolation or in combination, were acceptable treatments Psychosocial treatment with pharmacological treatment resulted in unacceptable ratings

Table 1 continued

Study citation	Study design/methods	Sample characteristics	Factors associated with adherence to treatments for ADHD			
			Personal characteristics (socio-demographic and diagnostic)	Structural barriers	Perception of ADHD	Perception of treatment
Thiruchelvam et al. (2001)	Prospectively followed children with ADHD who had been prescribed methylphenidate for 3 years	71 children with ADHD; aged 6–12	Decreased adherence related to increased age of child; presence of ODD at school and more teacher-rated symptoms of ADHD related to better adherence			
Wilson and Jennings (1996)	Alternative treatments for ADHD were evaluated using questionnaires	96 parents were randomly assigned to either a "psychosocial treatment + stimulant" or a "psychosocial treatment only" condition				Psychosocial treatment, in combination with stimulant medication, was rated as significantly less acceptable than psychosocial treatment alone
Zima et al. (2012)	Longitudinal cohort study of children receiving care for ADHD in a large national Medicaid program	529 children, aged 5–11, and their parents		Concerns about talking to their doctor (20 %) Fears about losing custody of their child (17 %) Logistical problem (i.e. cost, transportation; 42 %) Clinic-related problem (i.e. wait; 31 %)		Stigma (15 %)

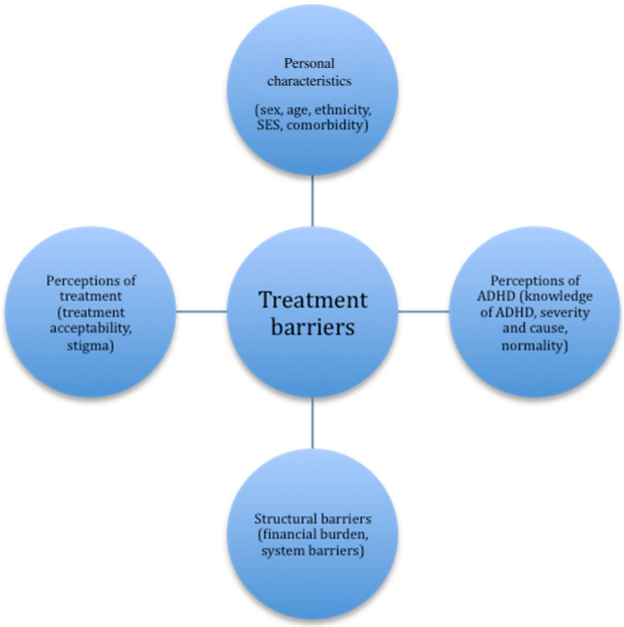

Fig. 1 Four main sections of the review

Moreover, another study found that boys in their sample of children at high risk for ADHD were five times more likely to receive an evaluation, diagnosis, or treatment than girls (Bussing et al. 2003b).

Graetz et al. (2006) compared service use patterns and associated factors for 398 children (279 males) with ADHD. Similar to previous research, the main finding was that proportionately more boys than girls received medication. Although boys and girls did not differ in terms of their rates of counselling service use or the types of services they used, the factors associated with service use were different between sexes. For boys, academic problems and the number of behavioural symptoms were the main predictors of service use, whereas for girls, the presence of a comorbid depressive disorder was the main predictor (Graetz et al. 2006). One study reported that females were both more adherent to and persistent with treatment than males (Barner et al. 2011). Adherence was defined as the number of days the patient was in possession of their medication, while persistence was defined as the number of days of continuous therapy (Barner et al. 2011).

(ii) *Age of child* In general, younger children are more likely than adolescents to comply with prescribed pharmacological treatment (Atzori et al. 2009; Barner et al. 2011; Berger-Jenkins et al. 2012; Gau et al. 2008; Miller et al. 2004; Thiruchelvam et al. 2001). In contrast, Ohan and Johnston (2000) had 44 parents and adolescents make a general estimate of the adolescents' adherence to medication. In addition, participants were asked to estimate the number of doses taken over the past week and over the past 24 h. This information was collected during an initial interview and again after 2 months. Nearly half of the parents and adolescents reported over 90 % adherence at both time points. The authors did not expect adherence rates to be this high and offered several potential explanations. For example, the sample was drawn from adolescents who were currently being prescribed medication and excluded those who were not seeking medication even if they might have benefited from it (which could be interpreted as non-adherence). Furthermore, participants could have overestimated or been deceptive with their reports. Also, the sample could be biased towards low-conflict homes in which the parent and adolescent were willing to participate in research together, possibly eliminating participants from high-conflict homes. Another offered explanation was that anecdotal reports of low adherence rates in adolescents may be biased by the saliency of the "difficult-to-treat" minority of adolescents.

(iii) *Ethnicity* There is little research specifically investigating ethnicity in relation to adherence and uptake of psychosocial interventions for ADHD. Some reports indicate that children from minority ethnic groups were generally less likely to accept and receive services for ADHD than were Caucasian children (Bussing et al. 2003b; dos-Reis et al. 2003; Hong et al. 2013; Krain et al. 2005; Palli et al. 2012; Ray et al. 2006; Schneider et al. 2013; Stevens et al. 2005). However, some studies found that ethnic minority parents were equally likely to find treatments acceptable (Arnold et al. 2003; Tarnowski et al. 1992). Krain et al. (2005) results indicated that 79 % of Caucasian parents in their study pursued medication as a treatment for their child's ADHD, while only 27 % of non-Caucasian parents did so. In Bussing et al. (2007) study, which explored cultural variance in parental health beliefs and knowledge and information sources related to ADHD, African American parents reported less awareness of ADHD and rated their own knowledge of ADHD lower than their Caucasian counterparts. They also reported receiving fewer cues to action, such as being given ADHD information from teachers or reading media accounts, than their Caucasian counterparts.

A number of researchers have proposed that one possible explanation for why children from minority ethnic groups are less likely to receive treatment is that their cultures foster different beliefs and attitudes about mental health disorders and appropriate treatments. For example, Arcia et al. (2004) found that Latina mothers were concerned that stimulant medications had serious side effects or that their children would become addicted to stimulant medications.

(iv) *Socio-economic status (SES)* Research indicates that families with lower SES are less likely to pursue and/or adhere to treatment for ADHD (Arnold et al. 2003; Brown et al. 1987; Bussing et al. 2003b). Rieppi et al. (2002)

studied several SES variables within a large sample from a randomized clinical trial of treatments for ADHD (i.e. Multimodal Treatment Study of Children with ADHD). Overall, they found that rates of adherence were significantly related to parents' income, education, and job status, with higher levels of these three variables associated with greater treatment adherence. When types of treatments were analysed separately, they found that medication adherence was not related to any of the SES variables. In contrast, adherence to psychosocial and combination treatment regimes was significantly related to all of the SES variables. In addition, families who regularly attended psychosocial treatment sessions were significantly more likely to include two-parents. Others, however, have contradicted these findings (Brownell et al. 2006). Their results showed that the probability of methylphenidate use (i.e. adherence rate or prescription rate) at the end of a 2-year longitudinal study was inversely related to SES. Specifically, as SES decreased, methylphenidate use increased. Thus, the impact of SES on treatment utilization and adherence appears to vary by treatment type, with stimulant medication rates being either unaffected or increasing with lower SES, and psychosocial treatment and adherence increasing with higher SES.

(v) *Comorbid diagnoses* Little research has investigated the impact of comorbid diagnoses on issues related to ADHD treatment utilization and adherence. As mentioned previously, one study found that girls with ADHD and comorbid depression were more likely to receive and adhere to intervention than were girls with ADHD who were not depressed (Graetz et al. 2006). Sitholey et al. (2011) found that children with comorbid mental retardation (now "intellectual disability" in the DSM-5) were less likely to adhere to treatment. In a longitudinal study (Thiruchelvam et al. 2001) that followed 71 children with ADHD who were prescribed methylphenidate over 3 years, medication adherence decreased over time and having a comorbid diagnosis was significantly associated with treatment non-adherence. Specifically, children with high levels of oppositional defiant disorder (ODD) symptoms at school were 11 times more likely to discontinue medication than children without ODD symptoms. Anxiety was also identified as a moderator of adherence. Conduct disorder (CD) and learning disorder (LD) were also analysed but were not found to have a moderating effect. The results of these studies suggest that comorbid disorders may be important factors in the utilization of and adherence to treatment, and that further research is needed to delineate which disorders are of greatest consequence and in which populations.

2. Structural barriers

Structural barriers are the characteristics of the treatment, the health system, or the family that make it challenging for families to initiate or comply with treatment. This term encompasses the logistical elements of treatment, including cost, time requirements, transportation, availability of service providers, etc. Of the 63 studies reviewed, 22 studies examined structural barriers to treatment, including: (i) financial burdens and (ii) system barriers (i.e. counselling feasibility and medication inconveniences).

(i) *Financial burden of treatment* One of the primary structural barriers identified in this review was the financial cost of the treatment for ADHD (Chan et al. 2002; Guevera et al. 2001; Kelleher et al. 2001; Sawyer et al. 2004; Sitholey et al. 2011). Bussing et al. (2003b) found that of the 91 families in their study who had not received treatment, 38 % reported that the main reason they did not pursue treatment was the cost. Annual medical costs for children with ADHD tend to be more than double the cost for children without ADHD (Leibson et al. 2001). In a study that compared treatment costs for asthma compared to ADHD, families of children with ADHD paid more prescription-related costs and out-of-pocket expenses (Chan et al. 2002). Moreover, Swensen et al. (2003) found that parents and siblings of a child with ADHD were also more likely to have increased medical costs, often due to the stress incurred from having a child/sibling with ADHD (twice as much for families with a child with ADHD vs. matched comparison families). Cost may also interact with SES to impact treatment utilization and adherence, as cost would likely be a larger barrier for families of lower SES than for families of higher SES. It is also important to note that the cost of treatment and the availability of service providers are factors that vary across countries and cultures.

Having a child with ADHD can also have a significant impact on parents' employment. While a study by Perrin et al. (2005)[1] did not meet the criteria of our review, it does provide important information. The authors interviewed employers of 41 companies across the USA to find out how supportive their policies were for employees who have children with ADHD. The interviews included questions regarding: (1) knowledge of ADHD diagnosis and prevalence, (2) knowledge of associated costs, (3) general philosophy regarding benefits, and (4) knowledge of how ADHD impacts employees. They found most employers did not realize the significant burden placed on families who have a child with ADHD and that most company insurance policies were not supportive in terms of the needs for families with a child with ADHD. For example, most companies did not cover the cost of behavioural therapy.

[1] This study was not included in our review, but provides important context for the overall paper.

(ii) *System barriers* System barriers are features of the healthcare and social system, broadly defined, that affect the likelihood that a person will accept and adhere to treatment. System barriers are experienced by between 35 and 53 % of families attempting to obtain treatment for their child with ADHD (Bussing et al. 2003b; Owens et al. 2002). Barriers such as lack of time, lack of teacher cooperation, advice from child's school, lack of insurance coverage, frustration with guidance provided, and problems in hospitals (e.g. long waiting time) have been identified (Brinkman et al. 2009; Cormier 2012; Davis et al. 2012; Dreyer et al. 2010; Sitholey et al. 2011; Stevens et al. 2005; Zima et al. 2012). Bennett et al. (1996) hypothesized that counselling feasibility (e.g. scheduling flexibility, travel distance) would predict adherence to treatment, as found in earlier research. Only 54 % of their sample initiated the recommended counselling; however, they did not find a relationship between parent-rated counselling feasibility and adherence. Therefore, it seems as though there are other factors above and beyond feasibility that predict adherence.

The inconvenience of taking medication several times per day has been noted as a barrier for adherence to stimulant medications for ADHD (Barner et al. 2011; Gau et al. 2006, 2008; Sitholey et al. 2011). Certain types of stimulant medications are now available in extended-release (long-acting) form, which requires only one dose per day (Rothenberger et al. 2011). Reducing the number of doses per day creates a simpler medication regimen and has been found to increase compliance with taking stimulant medication for ADHD (Marcus et al. 2005). Physicians are moving away from prescribing short-acting medications, with one study finding that prescriptions for short-acting medications have been on the decline since 1999 (Scheffler et al. 2007) (see footnote 1). Despite their convenience, long-acting medications are more costly than short-acting medications (Scheffler et al. 2007). While the Scheffler et al. (2007) study did not directly assess barriers to treatment for ADHD and therefore was not included in our review, it can be theorized that cost of medication may interact with SES. The issue of medication cost may make short-acting medication more available to families of lower SES, which could increase the burden of structural barriers and contribute to non-adherence to medication as a treatment.

Some children are physically unable to swallow pills or experience severe anxiety when attempting to do so (Beck et al. 2005). A significant problem for children with pill-swallowing difficulties is that some of the newer extended-release forms of stimulant medication cannot be crushed prior to ingestion (Beck et al. 2005). One solution to this problem has been to implement a behavioural training program for pill-swallowing. Beck et al. (2005) applied this approach for children with ADHD and achieved high levels of success. Another alternative has been developed recently in the form of a transdermal system (i.e. a patch), which adheres to the skin and releases methylphenidate (Pelham et al. 2005) (see footnote 1). This study did not meet the criteria for our review, but offers an alternative to pills, which may improve adherence. The patches were generally well tolerated by study participants, with a small minority of children reporting mild discomfort during removal. This system could help solve the problem of remembering to take a pill several times per day and could be helpful for children who find swallowing pills difficult. However, this patch is not available in all countries.

3. Barriers Related to Parents' Perception of ADHD

This cluster of barriers refers to the way in which parental knowledge and beliefs regarding ADHD can affect decisions to pursue and adhere to treatment. Studies that discussed these barriers referred to: (i) the amount of knowledge a parent has about ADHD, (ii) how much parents perceive the disorder to impact their child/family life, and (iii) their opinions regarding the cause of ADHD. Of the 63 studies, 20 studies addressed these barriers.

(i) *Knowledge of ADHD* research has demonstrated that treatment patterns for children with ADHD can vary based on how much their parents know about the disorder. For example, Bennett et al. (1996) and Liu et al. (1991) found that the more parents knew about ADHD, the more accepting they were of medication as a treatment. In addition, Corkum et al. (1999) found that families were more likely to enrol in treatment if they had higher knowledge of ADHD; however, knowledge of ADHD was not related to adherence. Bailey and Owens (2005) found that lack of knowledge about ADHD was a significant barrier to treatment for African American children. Sitholey et al. (2011) identified parents' notion that ADHD symptoms will subside on their own as a barrier to treatment in 30 % of their sample.

One large-scale study included 658 families of children with ADHD, for which parents had either declined or discontinued medication for their child (Monastra 2005). In this study, 90 % of the sample had previously reported feeling uncomfortable putting their children on medication without a direct test of attention. To address this, the researchers administered both computerized and electro-encephalographic quantitative evaluations of attention to all children in the study. The results of these tests were presented to parents in combination with a neuro-educational intervention program about ADHD. In addition, a comprehensive care plan treatment manual was sent home. Following these procedures, over 70 % of parents started their children on a pharmacological treatment. At the 2-year follow-up, 95 % of the initial group of children were

still taking medication for ADHD. Therefore, it appears that adequate information about ADHD and treatments can substantially increase uptake and adherence.

(ii) *Perceived severity and cause of symptoms* The way a parent perceives the behaviour of his or her child can influence the decision to pursue, accept, and adhere to treatment (Angold et al. 1998; Brownell et al. 2006; Charach et al. 2004; Maniadaki et al. 2006; Owens et al. 2002; Sayal et al. 2006; Sawyer et al. 2004; Tarnowski et al. 1992). It has also been found that parents who perceive their career is being negatively affected by their child's behaviour are more likely to seek treatment (Sayal et al. 2003). Stigma and scepticism of diagnosis have also been identified as barriers to beginning treatment (Ahmed et al. 2013a; Bailey and Owens 2005; Brinkman et al. 2009). Believing that their child would outgrow the disorder (Cormier 2012) or that the disorder was caused by poor parenting also delayed treatment (Davis et al. 2012). These beliefs about cause of disorder may differ across culture; for example, Bussing et al. (2007) found that African American parents attributed more causation to sugar intake.

4. Barriers related to perceptions about treatment of ADHD

The final barrier category identified in this review is related to perceptions about treatment for ADHD (addressed by 28 of the 63 studies included in the review). Treatments for ADHD, especially stimulant medications, have been widely publicized in the media. Therefore, many parents have preconceived notions about various treatments—often based on misconceptions—which can prevent them from obtaining and/or adhering to treatment for their child. Categories included in this section are (i) treatment acceptability and (ii) stigma-related barriers.

(i) *Treatment acceptability* Treatment acceptability refers to the beliefs and attitudes regarding which treatments are appropriate, fair, and reasonable, given the nature and severity of the problem (Kazdin 1981). The present literature review revealed the robust finding that parents rate psychosocial treatments as more acceptable than pharmacological ones for children with ADHD (dosReis et al. 2006; Dreyer et al. 2010; Gage and Wilson 2000; Liu et al. 1991; Miltenberger et al. 1989; Monastra 2005; Power et al. 1995; Tarnowski et al. 1992; Wilson and Jennings 1996). This is likely due to parents' fears about personality changes, "zombie"-like side effects, and worries about future substance addiction (e.g. Ahmed et al. 2013a; Davis et al. 2012). In addition, interventions that emphasize positive reinforcement rather than punishment, and those that require relatively little time and effort, are perceived as more acceptable to parents (Reimers et al. 1992). Studies have shown that parent acceptability of and attitudes towards treatment are related to treatment seeking and adherence (Bird et al. 2008; Corkum et al. 1999). Medication concerns have also been associated with less follow-up and less utilization of treatment (Berger-Jenkins et al. 2012). Several other factors, including a child's history of medication use and counselling for ADHD (Rostain et al. 1993) (see footnote 1) have also been shown to be positively related to parent acceptability of ADHD interventions.

In a study by Krain et al. (2005), parent acceptability accurately predicted initiation of medication 3–4 months later in 83.7 % of cases. However, acceptability of behaviour therapy did not predict psychosocial treatment initiation. One reason the authors give for this finding is that ratings of behaviour therapy were consistently high, which did not provide enough variability to distinguish high and low acceptability. Some of the potential reasons put forth by the authors as factors that may have influenced the families' decision not to pursue behaviour therapy included unavailability of a qualified behaviour therapist, lack of time, and financial concerns. In contrast to these findings, Bennett et al. (1996) found no relation between parent ratings of counselling acceptability, medication acceptability, and adherence to recommendations for either type of treatment 4 months after acceptability information was collected.

As mentioned earlier, ethnic differences in treatment acceptability for ADHD have been reported in several studies. Bussing et al. (2007) found that African American parents expected less benefit from treatment. Similarly, another study reported that African American families had higher rates of negative treatment expectations (e.g. did not expect treatment would be successful, distrusted professionals; Bussing et al. 2003a). Arcia et al. (2004) found that Latina mothers had strong reservations about allowing their children to take stimulant medication. Families from minority backgrounds were also found to view medication as an unattractive treatment option, to be less satisfied with medication, and to be more likely to believe that medication for ADHD is associated with negative side effects (dosReis et al. 2003).

(ii) *Stigma-related barriers* Stigma-related barriers are those having to do with others' negative attitudes towards ADHD and ADHD treatment. Historically, there has been substantial stigma associated with mental health diagnosis and treatment. As noted by Johnston and Fine (1993) (see footnote 1), poor treatment adherence in the paediatric and ADHD research literature may be in part related to negative publicity surrounding particular interventions (e.g. stimulant medication), as well as concerns regarding side effects. This was demonstrated in our review, with several

studies finding fear of side effects to be a barrier (Ahmed et al. 2013a; Brinkman et al. 2009; Coletti et al. 2012; Cormier 2012; Sitholey et al. 2011). Although knowledge about the effectiveness of treatment has continued to grow and has been more widely disseminated, this stigma still exists and is particularly salient in the case of ADHD. Several studies in our review found stigma to be a barrier to treatment (e.g. Cormier 2012; Zima et al. 2012). Bussing et al. (2003b) found that 39 % of the parents they surveyed reported a stigma-related barrier to getting help for their child with ADHD. For example, parents reported concerns about being negatively perceived by others. In addition, parents reported stigma barriers more when they had a daughter with ADHD.

Researchers have, in part, blamed the media for its inaccurate portrayals of the disorder. While no studies included in our review assessed this directly, there has been some interesting research into the way that ADHD is portrayed in the media. Schmitz et al. (2003) (see footnote 1) examined social representations of ADHD that were located from print media sources (e.g. MacLean's, People Magazine) in the USA between 1988 and 1997. They concluded that ADHD was portrayed as a disorder that affected Caucasian males. Furthermore, the disorder was commonly reported as being over-diagnosed, and stimulant medication was portrayed as an over-prescribed treatment. These findings are consistent with Danforth and Navarro (2001) (see footnote 1), who had research assistants document any references to ADHD encountered in their daily lives in spoken, written, or other formats. They also concluded that the media was in part responsible for the stigma associated with ADHD by discussing ADHD in connection with tragic events like murders.

Conclusions

The present review was conducted to gain a better understanding of the factors that explain why a large percentage of children diagnosed with ADHD are not receiving evidence-based treatment. Our review, which is consistent with past reviews (e.g. Ahmed et al. 2013b; Calvert and Johnston 1990; Cromer and Tarnowski 1989; Reimers et al. 1987; Swanson 2003), indicates that there are many complex and interactive relationships among a variety of factors, all of which influence families' decision-making in regard to selecting and adhering to treatment(s) for children with ADHD. Our review identified four major gaps existing in the literature, which will need to be addressed in order to better understand the weight of each of the identified factors that impact utilization and adherence for treatment of ADHD in children.

One of the most apparent gaps is that the majority of the factors highlighted in this review are related to pharmacological treatment adherence. Although both pharmacological and psychosocial treatments are included in most of these studies, the weight of the research is concentrated on factors related to the utilization of and adherence to medication. Less is known about what influences parents' decision to enrol in and/or adhere to counselling, behaviour therapy, or other forms of psychosocial interventions.

The second gap in the literature is that the two types of non-compliance with treatment are often studied jointly. These are (1) treatment utilization (i.e. whether the family begins treatment), and (2) treatment adherence (i.e. whether the family continues treatment after starting). Although it seems likely that different factors contribute to each of these types of non-adherence, most of the research completed thus far has either failed to differentiate between the two or has focused only on non-adherence. Many of the samples in the studies reviewed here are comprised of parents who have already enrolled in treatment. This eliminates the possibility of learning about parents who declined treatment altogether.

The third gap is that most of the information in the current review comes from research that was completed with parents. Research is greatly needed that includes the perspectives of other people involved in the care of children with ADHD, such as clinicians, family physicians, and teachers of children, as well as youth diagnosed with ADHD. Gaining the opinions and knowledge from a more varied sample of individuals who work with and care for youth with ADHD, as well as from the youth themselves, is essential to developing a broad understanding of why many children with ADHD are not receiving sufficient treatment.

The fourth and final gap in the literature is the use of limited types of methodology. Most of the studies were based on the results of questionnaires given to parents of children with ADHD. This is an efficient way of obtaining a large amount of data quickly; however, more varied methods (including both qualitative and experimental research designs) must be employed in order to gain comprehensive information that can be applied in clinical settings. Moreover, many of the studies focused on specific, isolated variables such as ethnicity or gender. Studies are needed that examine a range of variables, including those identified in this review, and that employ a variety of methodologies within a single, representative sample.

It is also interesting to consider how these barriers to treatment for ADHD differ from barriers to treatment for other chronic health conditions, such as depression, diabetes, and arthritis. A study by Shen et al. (2013) found that barriers to treatment for diabetes include a lack of trustworthy information sources, deficits in communications between clients and healthcare professionals, and

restrictions of reimbursement regulations (i.e. financial burden). A study examining barriers to pain management in patients with arthritis found that the primary barriers were surrounding worries about medication side effects, concerns about drug interactions, and fear of addiction (Fitzcharles et al. 2009). Barriers to depression treatment have been identified as lack of readiness to seek help, negative perceptions about medication, and transportation concerns, among others (Wells et al. 2013). These barriers are similar to those identified in this review, indicating that similar barriers are at play across different chronic health conditions.

In summary, more research is needed to further understand the complexity of ADHD treatment barriers and how these factors interact. Given the high prevalence rates of ADHD, the known negative impacts across multiple domains of functioning, and the strong empirical evidence for the effectiveness of a number of treatments, it is crucial to further examine why children are not receiving evidence-based treatments. In order to fully understand and ultimately overcome these barriers, studies are urgently required that include multiple variables and use divergent methods within a single representative sample. Another important area of future research would be to develop a model of adherence, which would facilitate focused research in this area and ultimately allow for a quantitative review of adherence to be conducted. Information about treatment barriers will help to inform the type of education required to ensure that parents and their children with ADHD initiate and adhere to evidence-based treatments.

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*Asterisks indicate which articles are included in the table

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