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Recommended Citation
Pajo, B., & Cohen, D. (2013). The problem with ADHD: Researchers' Constructions and Parents' Accounts. *International Journal of Early Childhood, 45* (5) Retrieved from https://fuse.franklin.edu/facstaff-pub/13

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IJEC
DOI 10.1007/s13158-012-0064-z

ORIGINAL ARTICLE

The Problem with ADHD: Researchers' Constructions and Parents' Accounts

Bora Pajo · David Cohen

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Abstract An enduring controversy over the nature of ADHD complicates parents' decisions regarding children likely to be diagnosed with the condition. Using a fallibilist perspective, this review examines how researchers construe ADHD and acknowledge the controversy. From a systematic literature search of empirical reports using parents of ADHD-diagnosed children as primary informants, 36 reports published between 1996 and 2008 (corresponding to 30 studies) were selected. Data on the studies' characteristics and methodologies, definitions of ADHD, and extent of the acknowledgment of the ADHD controversy were extracted, as were data on a wide range of parental concerns and experiences. Researchers in 27 of 30 studies define ADHD as a valid disorder, in 22 studies they tend to recommend parental adherence to the biomedical view, and in eight studies they specifically acknowledge an ADHD controversy. This body of studies reports varied and poignant observations on parents' situations and dilemmas. Still, it largely reflects a Western-ethnocentric view and appears greatly preoccupied with parents who do not medicate their children, ignoring parents' rationales for using medications.

Keywords Attention-deficit hyperactivity disorder construct · Researchers' views · Parents' views · Fallibilism · Critical perspective · Qualitative studies

Résumé La nature du trouble de déficit d'attention/hyperactivité (TDAH) fait toujours l'objet d'une vive controverse, ce qui complique les décisions des parents d'enfants susceptibles d'être diagnostiqués. Dans une perspective faillibiliste, cette

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Published online: 20 July 2012

recension examine comment les chercheurs conçoivent le TDAH et reconnaissent cette controverse. Suite à une recherche systématique de rapports empiriques dont des parents d'enfants diagnostiqués de TDAH sont les informateurs principaux, 36 publications (correspondant à 30 études), parues de 1996 à 2008, ont été sélectionnées. Nous en avons extrait les données sur les caractéristiques, les méthodologies, les définitions du TDAH, le degré de reconnaissance de la controverse, ainsi qu'une grande variété de ce que ces études rapportaient des expériences et des préoccupations des parents. Dans 27 des 30 études, les chercheurs définissent le TDAH comme une entité clinique valide, dans 22 études, ils tendent à recommander l'adhésion des parents au point de vue biomédical et, dans 8 études, ils reconnaissent spécifiquement une controverse relative au TDAH. On trouve dans ce corpus nombre d'observations poignantes sur les situations et les dilemmes des parents. Il reflète néanmoins largement un point de vue ethnocentrique occidental, où la préoccupation principale semble résider dans le fait que certains parents ne donnent pas de médicaments à leurs enfants, ignorant les motifs des parents pour utiliser la médication.

Resumen Una constante controversia sobre la naturaleza del Síndrome de Déficit de Atención con Hiperactividad (SDAH) complica las decisiones de padres de familia de niños que podrían ser diagnosticados con esta condición. Usando una perspectiva aún falible, pero extensa, esta evaluación examina cómo los investigadores interpretan SDAH y reconocen la controversia. Desde una revision sistemática de la literatura investigativa de reportes empíricos, en que se incluía a padres de familias con niños diagnosticados con SDAH como informantes primarios, se seleccionaron 36 reportes publicados entre 1996 y 2008 (correspondientes a 30 estudios). Se extrajo información de las características y metodología de los estudios, definiciones de SDAH, y el extenso y polémico conocimiento de SDAH, como también información del amplio rango de preocupaciones y experiencias de los padres de familia. Investigadores en 27 de 30 estudios definen SDAH como un desorden válido, en 22 estudios tienden a recomendar a los padres adherencia a la opinión biomédica y en 8 estudios reconocieron específicamente una controversia de SDAH. Este cuerpo de estudios reporta observaciones de situaciones diferentes y penosas de los padres de familia. Aún más, refleja claramente una visión etnocéntrica occidental que parece enormemente preocupada por los padres que no medican a los niños, ignorando el juicio y razones de los padres para usar o no utilizar medicamentos.

Introduction

Because of their involvement in all decisions related to diagnosing and treating attention deficit/hyperactivity disorder (ADHD) in their children (Hansen and Hansen, 2006), parents may be posited at the core of this phenomenon. Parents usually first notice their children's differences or difficulties or are first notified by teachers about ADHD-like behavior or school problems (Sax and Kautz 2003). Professionals who evaluate children listen to parents' descriptions and often have

them fill out behavior rating scales. Parents make treatment decisions based on professionals' recommendations, their own cognitive schemas (Arcia et al. 2004), opinions from friends and relatives (Jackson and Peters 2008), and media reports (Taylor et al. 2006). Parents' decision-making, however, is complicated by an enduring controversy among experts and laypersons about the nature of ADHD and the benefits of long-term use of stimulants (Mayes et al. 2008). Knowledge on what bothers parents about their children's behavior, how they view their options, and what they see as the consequences of their choices remains largely anecdotal, although studies have attempted to capture parents' views and experiences on these issues. To accurately conceptualize the findings of this body of research, however, it seems necessary to first understand the framework used by researchers to capture parents' views and experiences. In this review, we use the enduring ADHD controversy as a lens to examine how, in empirical studies that elicit parents' views and experiences about their children's ADHD, researchers construct these parents' problems and their children's problems.

The ADHD controversy

In the United States between 1996 and 2006, the prevalence of the ADHD diagnosis increased by 3 % annually, and an average of 5.5 % from 2003 to 2007 (Pastor and Reuben, 2008). In 2007, 9.5 % of US children aged 4–17 years were diagnosed as having ADHD, 2.7 million of which (66.3 % of children diagnosed) were prescribed stimulants such as methylphenidate and amphetamines (CDC 2010). Yet, controversy about ADHD has existed since the first use of stimulants with school children in the late 1960s (Schrag and Divorky, 1975) and the subsequent inception of the diagnostic term in the third edition of the diagnostic and statistical manual of mental disorders (DSM) in 1980, and the expansion of the diagnostic category in the fourth edition in 1994 to include signs of hyperactivity, impulsivity, and inattention (American Psychiatric Association 2000). Today, most experts might maintain that ADHD refers to a disorder of impulse control (Barkley 2000) and impaired working memory (Rucklidge 2006) accompanied by brain volume abnormalities (Castellanos et al. 2002). Others use the term only to indicate the lack of fit of a child's temperament with a structured environment (Diller and Tanner 1996), a label for normal disruptive or inattentive children (Stolzer 2005), or a only a culturally-situated construct (Timimi and Taylor 2004). ADHD is variously called a "condition", "disorder", "disability", or "disease" (Arcia et al. 2004), but occasionally an individual "difference" (Carpenter and Austin 2007), even an "evolutionary advantage" (Armstrong 2006). The variety of labels reflects the failure to biomedically detect or confirm ADHD despite the primacy of the biomedical perspective to account for it theoretically. Debates between professionals about the validity of an entity ADHD have been heated (Barkley et al. 2002; Jureidini 2002). Proposed revisions to the ADHD diagnostic criteria for DSM-V, scheduled for publication in 2013, still include no neuropsychological or biological criterion.

Debates between professionals have notably focused on the use of psychotropic drugs to treat ADHD. Drugs' short term ability to reduce ADHD symptoms is well

established (Biederman et al. 2006), but routine adverse effects such as insomnia, appetite and weight loss, increased blood pressure, depression, and temporary growth suppression worry some observers (Breggin 2000). Although the ADHD controversy has lessened lately in the United States—possibly as other disruptive early-childhood behaviors became medicalized and other psychotropic drugs such as antipsychotics became increasingly prescribed to children (Azerad 2010)—researchers observed an association between methylphenidate use and sudden unexplained death among children without prior heart conditions (Gould et al. 2009), leading to renewed debate (Vitiello and Towbin 2009). Moreover, situational factors such as later birth date relative to other children in the same grade have been shown to increase a child's likelihood of being diagnosed with ADHD and receiving stimulants by 40 percent (Elder 2010). Such controversies are widely aired by the media. Undoubtedly, parents of children diagnosed with ADHD are interested, if not confused or worried, listeners.

The ADHD controversy suggests that researchers count among the stakeholders in the ADHD phenomenon, approaching their investigations with varying assumptions about ADHD, its management, and the choices facing parents. According to Popper (1963), knowledge may be conceptualized as scientific only to the extent that it leaves itself open to criticism and researchers seek to devise tests to falsify reigning hypotheses. Given an assumed characteristic of knowledge as provisional and conjectural, progress in a field of investigation thus largely rests on the willingness to submit its key constructs to refutation, because findings that result from attempts to refute key constructs typically raise new problems that demand explanation.

In this article, we focus on studies that have sought to identify the concerns of parents who raise children diagnosed as ADHD, and we assess to what extent these studies reflect a fallibilist ideal. Because most relevant studies that we located are social qualitative studies resting on induction, however, we judged that the issue of tests designed to attempt falsification of reigning hypotheses was less relevant than the researchers' "critical attitude" (Popper 1999), which we operationalized in this study as researchers' openness to *acknowledging that an ADHD controversy exists*. In the contemporary environment, where the preeminent biomedical perspective passively or actively marginalizes competing discourses on the nature of ADHD (Visser and Zenib 2009), acknowledging the existence of the ADHD controversy could constitute a measure of the researcher's willingness to remain self-critical, if not to entertain falsification of the ADHD construct. Inversely, a lack of acknowledgment of the controversy would signify the opposite. Moreover, we supposed that the presence or absence (or degree) of any acknowledgment might be associated with different sorts of research concerns or problem statements. According to one review, peer-reviewed publications and popular media articles published between 1987 and 1998 implied or stated that ADHD is a condition rooted in children's brains (Schmitz et al. 2003). We thus expected that studies with parents of ADHD children would primarily rely on this reigning perspective, as would the interpretation of parents' accounts. Yet, we also expected that the seemingly inescapable ADHD controversy would find its way into the accounts of parents and in the constructions of researchers. Thus in this review, we attempt:

1 to conceptualize how—in empirical studies using parents of ADHD children as primary informants—researchers construe ADHD and the controversy over its nature; and
2 to draw possible links between these empirical studies' findings on parents' views and concerns and researchers' constructs of ADHD.

In the discussion, we try to use our findings from both efforts above to advance research into, and understanding of, the ADHD phenomenon.

Methodology

Search strategy and selection of publications

Searching for English-language publications appearing before November 2008 in the *ERIC, MEDLINE, PsycINFO, Social Work Abstracts,* and *Sociological Abstracts* databases, we included keywords (parents, children, attention deficit hyperactivity disorder, and their variants) appropriate to each database. This yielded 689 records, of which we selected 224 on the basis of format (peer-reviewed articles and chapters), title, and non-duplication. Dissertations were excluded because of difficulties in retrieving the entire text, and challenges in examining and comparing their extended information with limited information from journal articles. Subsequent inclusion and exclusion criteria narrowed the literature to empirical studies using parents as primary informants on their views and experiences related to any aspect of raising ADHD children. This produced 26 eligible reports. A manual search of their references yielded ten more publications, resulting in 36 included in this review (Fig. 1).

Data extraction

From the reports, we extracted data on:
1 studies' characteristics and methodologies;
2 researchers' ADHD constructs and broader theoretical perspectives; and
3 parents' views and concerns.

Data on the first two topics were extracted and summarized by each author independently. Data extraction on researchers' constructions focused on:
1 definition or description of ADHD (ADHD as a valid or questionably valid construct); and
2 degree of acknowledgment of the ADHD controversy (rated on a continuum, from no acknowledgement to detailed acknowledgement/discussion, see notes to Table 1. It is important to note here that In this rating we excluded any mention by researchers that ADHD lacks biological markers, because this is a known characteristic of the condition within the reigning biomedical view).

These data also included the studies' problem statements and any recommendations for practitioners. Data on parents' concerns and experiences focused on:

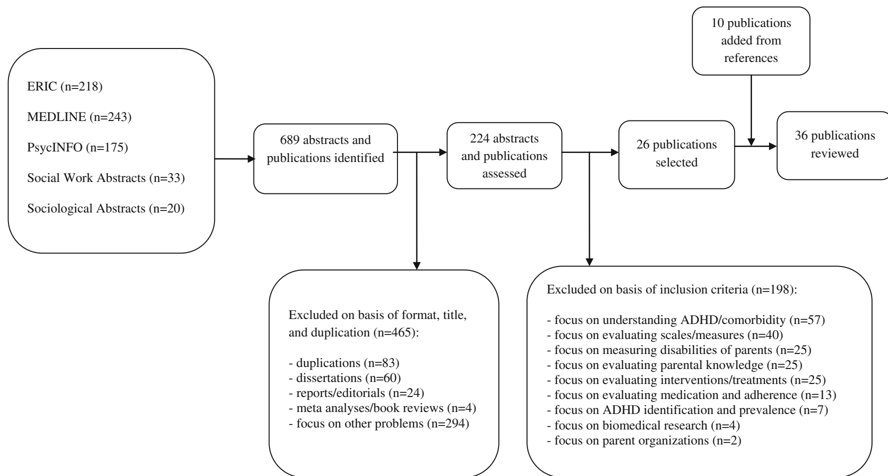

Fig. 1 Flow chart of search strategy

1. first identification of the problem and reactions to an ADHD diagnosis;
2. views about ADHD;
3. living with an ADHD child;
4. views about professionals; and
5. attitudes about, and experiences with, medications.

These data were extracted verbatim by B.P. from each report, then summarized iteratively by both authors. We did not attempt to "weight" themes and topics observed within studies, only identified their presence in parents' reported comments, and noted the number of studies expressing them. Summaries on all topics were then compared, discrepancies resolved by discussion, and conclusions reached by considering the findings in relation to each other and to the themes raised in the introduction.

Results

Characteristics of the studies

The 36 reports, published between 1996 and 2008, correspond to 28 studies conducted in English-speaking Western nations (14 in US, five in Canada, five in UK, four in Australia), and two studies conducted in India and Iran. The journals (and one book) publishing them represent the medical, behavioral, educational, and social science disciplines. Authors were affiliated with psychiatry ($n = 11$ studies), nursing, psychology ($n = 5$ each), education ($n = 3$), social work, health services, pediatrics ($n = 2$ each), and sociology, social studies, and social pharmacy ($n = 1$ each). Authors of three studies were affiliated with more than one discipline.

Table 1 Studies' problem statements and recommended applications

Authors (year)	Acknowledgment of ADHD Controversy[a]	Theory	Problem statement	Recommended application[b]
Studies that consider ADHD a valid disorder				
Arcia and Fernández (1998)	0	–	Little is known of Latina mothers' schemas of ADHD and the factors that shape them	Understand parents' schemas about their children and expand and modify such schemas as necessary. Do not present parent training as parent training but as paraprofessional training
Arcia et al. (2004)	0	–	Little is known of Latina mothers' cognitions and attitudes toward the use of medications	Include a blind medication trial as a planned strategy with a reluctant mother and make her a partner in the decision of an appropriate dose. Do not titrate dose on the basis of maternal feedback when administration has been sporadic or only during school hours when mothers cannot observe its effect. Do not accept at face value a maternal report that a medication has not been effective if a mother expects psychostimulants to change unmedicated behavior
Arcia et al. (2005)	0	–	The research on parental cognitions about children with disruptive behaviors has been limited in quantity and in scope	
Fernández and Arcia (2004)	0	–	Reactions to perceived stigma may shape the behaviors of mothers (especially Latina) as they cope with their children's behaviors and as they face possible pathways to mental health services	
Bussing and Gary (2001)	0	–	How do parents' ADHD assessment and chosen treatment differ from professional practice guidelines?	To increase congruence with professional guidelines, become aware of the discrepancy between practitioners' views and parents' lived experiences and be open to discussions

Table 1 continued

Authors (year)	Acknowledgment of ADHD Controversy[a]	Theory	Problem statement	Recommended application[b]
Concannon and Tang (2005)	0	–	There remains uneasiness among parents and professionals about various aspects of the management of ADHD	Be aware of parents' use of non-conventional therapies and ask about them in a non-judgmental way. Doctors should spend more time with families and give them adequate explanations about diagnosis and options. Teachers need more education about the effects of ADHD
DosReis et al. (2007)	0	–	No studies have explored the complex processes and motivations involved in managing the daily challenges of children with emotional and behavioral problems among minority families in urban, low-income neighborhoods	(It will be useful to identify patterns of parental adaptations most predictive of effective ADHD management)
DosReis et al. (2003)	0	–	Little is known about parental perceptions of medication	
Johnston and Freeman (1997)	0	–	Causal attributions for child behavior differ for parents of children with ADHD and parents of children with no behavior disorders	
Johnston et al. (2005)	0	–	Although parents influence treatment decisions, their beliefs and attitudes have not been widely studied	Remain vigilant to the possibility of parental inaccurate beliefs of ADHD. Ask and consider parents' view of the disorder as you work together in establishing treatment plans that will meet the child's needs and be congruent with parents' beliefs
Reid et al. (1996)	0	–	It is important to know what parents think about whether ADHD should be included into IDEA	
Segal (1998)	0	–	Effective intervention in ADHD requires an understanding of families as groups who engage in shared occupations	(Parental routines need to be changed to fit ADHD children's needs)
Whalen et al. (2006)	0	–	Pharmacotherapy rarely normalizes the behaviors of children with ADHD. Little is known about the characteristics or impacts of these residual behaviors	Extend treatment targets beyond the identified child to include parents and perhaps other family members as well

Table 1 continued

Authors (year)	Acknowledgment of ADHD Controversy[a]	Theory	Problem statement	Recommended application[b]
Wright (1997)	0	–	Optimal ADHD treatment requires detailed monitoring of children	Cooperation between professionals in health, education, and social services is essential so children can be offered a range of treatments
Kendall and Shelton (2003)	0	Y	Knowledge is lacking on to how help families manage negative sequelae of ADHD	
Kendall (1998)	1	Y	Little is known about how families experience the disorder and manage their lives	Evaluate the mental health status, and recognize co-morbid conditions, of all family members
Leslie et al. (2007)	1	–	There is considerable variation in stimulant medication use among youths with ADHD. Parental beliefs may determine use of mental health services	Improve communication between providers and families
Olanyian et al. (2007)	1	–	Racial disparities in ADHD treatment rates are large and may be related to issues other than financial factors	Acknowledge different family and community views about what is a behavior problem, address concerns about medication dangers (especially drug addiction), and keep communication lines open with families
Perry et al. (2005)	1	–	Few studies have addressed how Latino families experience ADHD	Help reduce guilt and stigma in Latino families by providing accurate information about causes and treatments for ADHD, explaining nurses' roles with parents, and discussing how to monitor treatment effectiveness
Ghanizadeh (2007)	2	–	If Iranian parents hold views about ADHD that are inconsistent with scientific research, they may be less likely to accept proper mental health services	Announce the availability of resources for assessing and treating ADHD children in mass media
Blum (2007)	2	Y	Mothers face difficulties in managing invisible disabilities and dealing with school and care systems that encourage drugs	

Table 1 continued

Authors (year)	Acknowledgment of ADHD Controversy[a]	Theory	Problem statement	Recommended application[b]
Klasen and Goodman (2000)	2	–	Clashes of perspectives between parents and GPs can negatively impact compliance, satisfaction, and use of health care	When assessing children, explore family explanatory models, including views of professionals. Encourage families to screen problems at home to differentiate between hyperactivity and conduct disorder. Provide simple management strategies
Wilcox et al. (2007)	2	–	What are the explanatory models of parents whose children have been diagnosed with ADHD in India?	In developing countries, use locally acceptable models of illness to improve awareness of, and access to, child mental health interventions
Dennis et al. (2008)	3	–	The management of ADHD requires cooperation of professionals and parents	Provide a key worker for children and their families, clear dialogues between parents and professionals, accessible and well-advertised support
Charach et al. (2006)	4	–	What factors influence adherence to stimulants from the perspective of parents?	Offer frequent open discussions with parents since adherence to medications is an ongoing and evolving process
Hansen and Hansen (2006)	4	Y	Little is known about parents' perceptions and everyday experiences with medications	Talk more with parents to better understand their everyday experiences
Harborne et al. (2004)	4	–	How do children and parents make sense of the different causal models of ADHD?	Be aware of stigma families may feel and think carefully of the long-term impact of diagnosis on parents and children before making a diagnosis
Jackson and Peters (2008)	4	–	The ADHD controversy affects parents' decisions, with the consequence that children may not benefit from the most efficacious treatment (medication)	Reflect on your own thoughts and feelings about ADHD, so as not to contribute to the skepticism and doubt facing parents
Singh (2003)	4	Y	Fathers are absent from research, the clinic, and public forums on ADHD	Consider fathers' perspectives as they may have important insights into their children' behaviors, but resist seeing these perspectives as evidence to support a genetic theory of ADHD

Table 1 continued

Authors (year)	Acknowledgment of ADHD Controversy[a]	Theory	Problem statement	Recommended application[b]
Singh (2004)	4	Y	Mother-blame for ADHD is ubiquitous. Mothers might stand to gain most from the absolution promised by brain-blame	
Singh (2005)	4	Y	Bioethical analysis of issues raised by neurocognitive enhancement such as Ritalin use is detached from real-life decision-making	(Because the shift to long-acting stimulants reduces the number of moral decisions that parents must make, the resulting incremental changes in society require close and proactive scrutiny)
Taylor et al. (2006)	4	Y	In light of the ADHD controversy, how do parents decide whether or not to medicate their diagnosed child?	Prescribe long-acting stimulants to lessen stigma on children, and provide multi-modal treatment for children and resources to parents confronted with the decision to medicate
Studies that define ADHD as a questionable entity				
Carpenter and Austin (2007)	2	Y	Regardless of what they do, mothers of ADHD children will fail to live up to the motherhood myth and will be disabled as a result	
Cohen (2006)	4	Y	Children who manifest specific behaviors in school setting are medicated, but it remains unclear how this option arises	(In complex systems of care, implicit functions override individual actors' explicit intentions, i.e., in some school settings, use of medication is a foregone conclusion for referred children even before they are evaluated)
Malacrida (2001)	4	Y	ADHD's ambiguity helps to study resistance to professional surveillance and stigmatization	(Teachers are filling an uncomfortable role in the medicalization of ADHD)
Malacrida (2004)	4	Y	ADHD's controversy complicates the routine work of medicalization that non-medical personnel carry out	

[a] Reports were rated as follows: 0, no mention of a controversy; 1, brief, non-specific, or accidental (e.g., repetition of a finding) mention of a controversy in the conclusion of the report; 2, brief, non-specific mention of a controversy in the introduction of the report; 3, specific or detailed mention of a debate over the *causes* of ADHD, itself considered a valid entity; 4, specific or detailed mention of the controversy over the *existence* or *validity* of ADHD as a clinical entity

[b] Statements in parentheses are conclusions, not recommendations

Judging from authors' first names and any descriptions accompanying the articles, women were authors or co-authors of 30 (84 %) of the 36 reports, men of nine (25 %). Researchers in twenty-four studies used qualitative methodology (sample sizes ranged from five to 62), five used primarily quantitative approaches, and one, mixed methods (sample sizes ranged from 73 to 278). Convenience sampling was used in all but one study and control groups were present in only two studies. In total, 1521 parents participated (67 % specified as mothers, 12 % as fathers). Ten studies reported research grant support (five from the US National Institutes of Health, four from other non-profit governmental or university sources, and one from a pharmaceutical company).

ADHD constructs in relation to problem statements, recommended applications, and theoretical perspectives

ADHD constructs in relation to problem statements

In 27 of 30 studies researchers define or assert ADHD as a valid disorder. They define it as a "psychiatric disorder" (Bussing and Gary 2001; Dennis et al. 2008; Ghanizadeh 2007; Wilcox et al. 2007), "developmental disorder" (Arcia and Fernández 1998; Fernández and Arcia 2004; Johnston et al. 2005), "behavioral disorder" (Kendall and Shelton 2003; Perry et al. 2005), "childhood disorder" (Segal 1998; Reid et al. 1996), "neurobiological and neurodevelopmental condition" (Jackson and Peters 2008; Johnston and Freeman 1997), "neurodevelopmental disorder" (Taylor et al. 2006), "hyperactivity disorder" (Klasen and Goodman 2000), "invisible disability" (Blum 2007), "psychiatric illness" (Singh 2003), or, most often, simply as attention deficit hyperactivity disorder (Charach et al. 2006; Concannon and Tang 2005; DosReis et al. 2003; DosReis et al. 2007; Hansen and Hansen 2006; Harborne et al. 2004; Leslie et al. 2007; Olanyian et al. 2007; Whalen et al. 2006; Wright 1997). Among this group, however, the presentation of the ADHD controversy varies: 12 studies omit any discussion of a controversy, 10 studies include a non-specific mention, and eight studies provide a specific or detailed acknowledgment (Table 1).

In three of the 30 studies, authors avoid defining an ADHD condition. Rather, they variously introduce the term as a "psychiatric category… with cultural and historical ambiguity" (Malacrida 2001, p. 141), an identification of "difference labeled" as ADHD, whose existence as "some measurable objective reality is irrelevant" (Carpenter and Austin 2007, p. 661), or speak of "the questionable validity of the ADHD diagnosis" (Cohen 2006, p. 139).

In both definitional groups, we grouped the problem statements of the reports according to their level of acknowledgment of the controversy (Table 1). The grouping suggests that, despite some overlap, the issues of adherence to medication treatment, differences in families' pattern of medicating, and differences in schemas about ADHD among parents of different cultures dominate the problem statements in the first group of studies that have passively accepted ADHD as a valid disorder and make no or only a brief accidental mention of the controversy. In this group, children are seen to be at risk as parental practices deviate from the biomedical

norm (professional diagnosis and adherence to prescribed medication). When researchers do acknowledge a definitional controversy about ADHD, problem statements concern mother blaming, the moral implications of cognitive enhancement, mothers' and fathers' different perspectives, clashes of perspectives between professionals and parents, the complexity of parents' decision-making in the light of constrained school and care systems that encourage the use of psychopharmaceuticals, and parents' dilemmas in the midst of the controversy. Finally, within the subgroup of researchers who challenge the biomedical definition of ADHD, the problem statements concern the role of non-medical actors in the routine medicalization of childhood behaviors, the difficulties of mothers to comply with the myths of motherhood, and the observation that minors are at risk precisely because the biomedical norm is being adhered to (children are diagnosed and medicated for exhibiting ambiguously deviant behavior).

ADHD constructs in relation to recommended applications

As with the problem statements, recommendations or suggestions for clinicians, teachers, and policy makers made by researchers also seem to differ according to their stance on the nature of ADHD. As Table 1 shows, only among the group of researchers who present ADHD as a valid disorder do we find the recommendations that clinicians engage in discussions with parents to persuade them of the worth of the biomedical view concerning their child's situation. This view is less prominent among the studies where researchers acknowledge the controversy over the nature of ADHD (studies rated 2–4). Although in this second group one study suggests that practitioners should *not* reveal their own thoughts about ADHD, to avoid increasing parents' doubts and skepticism about medications (Jackson and Peters, 2008), this particular study differs from the others in its group by presenting the controversy as fueled only by the media. Other studies in this group recommend including fathers' perspectives in the evaluation of the child's problem (Singh 2003), using multimodal treatment besides pharmaceutical options, making resource materials available so parents can draw on additional assistance when confronted with the decision to medicate their children (Taylor et al. 2006), conversing with parents to better understand their dilemmas about medication use (Charach et al. 2006; Hansen and Hansen 2006), and keeping in mind parents' concerns about stigma (Harborne et al. 2004). Finally, among the researchers who avoid defining ADHD, none makes any explicit recommendations. Cohen (2006) concludes that in school systems, the medication option might be a foregone conclusion even before clinicians begin to evaluate children referred to them. The other two studies emphasize that teachers are filling an uncomfortable position in the medicalization process (Malacrida 2001, 2004) and that women need safe spaces to speak and be heard (Carpenter and Austin 2007).

ADHD constructs in relation to theoretical perspectives

We defined a theoretical perspective as any explicit, formal statement of the point of view of the researcher that framed a problem statement, led to a research question,

aim, or hypothesis, and assisted in interpreting the findings. We considered "grounded theory", which was mentioned in eight reports, as a technique used to code data and group codes into concepts and not as a theory (Wasserman et al. 2009). Eight of the 30 studies (27 %) included a theoretical perspective. Twenty-two of the 30 studies (73 %) lacked any mention of their studies' theoretical guidance. Relating this finding with researchers' constructs of ADHD reveals that only five of 27 studies that present ADHD as a valid disorder also state a theoretical perspective (symbolic interactionism: Kendall 1998; Singh 2003, 2004, 2005; Taylor et al. 2006; phenomenology: Hansen and Hansen 2006; and feminism: Blum 2007). Of note, these five studies also acknowledge the controversy over the nature of ADHD. About three quarters of researchers of the group of 27 studies are affiliated with medical disciplines and nursing. On the other hand, all three studies that question ADHD's reigning definition state a theoretical perspective: Foucauldian notions of the relationships between knowledge, power, and resistance (Malacrida 2001), constructivist analysis of medication as social and cultural phenomenon (Cohen 2006), and feminism (Carpenter and Austin 2007). Their authors are researchers in the social sciences.

Concerns of parents of ADHD children

First identification of the problem and reactions to the diagnosis

Six studies reported on the first identification of the child's problem. Parents usually seem unaware of, or unconcerned with, any problem with their child before the school years (Blum 2007; Cohen 2006; Leslie et al. 2007; Malacrida 2001; Perry et al. 2005). Once teachers notify them of academic difficulties, these come to the fore. First to detect a future ADHD child, teachers recommend professional evaluations (Cohen 2006; Ghanizadeh 2007; Malacrida 2004).

Parents' reactions to their child being diagnosed with ADHD was explored in depth by Taylor et al. (2006), of nine studies that reported such findings. The reaction is a troubled one. Taylor et al. concluded that parents' coming to terms with the diagnosis resembled a multi-stage grieving process because their child loses status as a "normal" child. Some parents, however, feel that the diagnosis offers no useful guidance to distinguish between ADHD and normal child behavior (Arcia and Fernández 1998; Blum 2007; Bussing and Gary 2001; Kendall 1998), and that there is too little time to make treatment decisions after the diagnosis (Charach et al. 2006), especially because of schools' pressure that the child begin medication (Cohen 2006). Some parents are afraid or embarrassed to have a diagnosed child (Taylor et al. 2006; Wilcox et al. 2007) but some feel relief from guilt and responsibility for their child's behavior (Harborne et al. 2004).

Views about ADHD

Among 12 reports with relevant information on this theme, parents's views on ADHD varied widely. In four studies, parents explain ADHD as an internally caused biological condition uncontrollable by the child (Harborne et al. 2004; Johnston and

Freeman 1997; Klasen and Goodman 2000; Taylor et al. 2006). Some parents report persisting difficulties to make sense of the condition (Kendall 1998) because their child's behavior appears highly inconsistent (Arcia et al. 2004). Other parents ascribe ADHD to temperament (Arcia et al. 2004) or poor parenting (Ghanizadeh 2007), refusing to consider it a bona fide illness or disorder (Wilcox et al. 2007). Singh (2003), who interviewed mothers and fathers separately, reports large discrepancies between their views, with fathers less willing to ascribe a medical cause to their sons' behaviors.

Compared with White American parents, African American, Latino, and Iranian parents put less faith in the medical diagnosis or in ADHD as a distinct condition. African Americans and Iranian parents see ADHD as resulting from a lack of parental discipline (Dennis et al. 2008; Ghanizadeh 2007; Olanyian et al. 2007), whereas Latinos view ADHD-like behavior as normal (Arcia et al. 2004). Latinos are also concerned about the stigma of mental illness for their ADHD-diagnosed child (Fernández and Arcia 2004; Olanyian et al. 2007).

Living with an ADHD child

Ten reports discuss living with an ADHD child. This is portrayed as a major challenge for parents that requires strict organizational skills, especially when readying children for school in the morning and finishing homework after school (Malacrida 2001; Segal 1998). Parents generally report feeling in constant chaos, struggle, disruption, and stress (Charach et al. 2006; Dennis et al. 2008; Kendall 1998). They risk their marriages, cannot function properly (Malacrida 2001), resent their circumstances (Taylor et al. 2006; Whalen et al. 2006). Living with an ADHD child also means living with blame (Blum 2007; Singh 2003). Mothers, especially, perceive themselves judged by teachers and doctors or reprimanded by society at large because of their child's behavior (Charach et al. 2006; Jackson and Peters 2008; Taylor et al. 2006). However, after their child was diagnosed and medicated, mothers felt they were now judged by friends, family, and media for medicating their child (Jackson and Peters 2008; Singh 2005; Taylor et al. 2006).

Views about teachers and physicians

All five studies exploring views about teachers depict the relationship between parents and teachers as turbulent and mutually suspicious. Mother-teacher relationships are problematic because of differing views on child behavior (Reid et al. 1996) or medication use (Malacrida 2004). Mothers feel blamed and misunderstood by teachers, see them as patronizing and unsympathetic (Harborne et al., 2004; Malacrida 2004). For some mothers, the educational system failed them (Reid et al. 1996); it is highly bureaucratic and difficult to navigate, impeding the search for solutions to their children's school difficulties (Blum 2007).

Eleven studies described animosity of parents toward doctors and other professionals. Parents depict professionals at times as blaming or highly judgmental (Fernández and Arcia 2004; Klasen and Goodman 2000; Malacrida 2001) or disbelieving (Klasen and Goodman 2000). These difficulties are reported to start

with parents' struggle to find an appropriate doctor for their child (Taylor et al. 2006), but no study discussed how parents actually found doctors. Studies report that mothers have to "battle" the health care system to gain entry and insurance coverage for their children, and they struggle with multiple professionals and with "clinical uncertainty" (Blum 2007; Harborne et al. 2004). Parents perceive doctors as interested solely in prescribing medication, not caring about the child's problem (Charach et al. 2006; Concannon and Tang 2005; Olanyian et al. 2007), lacking understanding of the family situation (Cohen 2006; Dennis et al. 2008), and taking only just a few minutes to arrive at a diagnosis (Cohen 2006).

Attitudes about and experiences with medication

Eight studies reported on parents' attitudes about medication. As the decision to medicate nears, situations become more complex. Parents are confused and apprehensive about psychiatric medications prescribed to their children (Arcia et al. 2004; Dennis et al. 2008; Hansen and Hansen 2006; Jackson and Peters 2008; Perry et al. 2005; Taylor et al. 2006). They commonly express concerns about side effects (Bussing and Gary 2001; Charach et al. 2006) and uncertainty that medication is the answer to their child's problem (Arcia et al. 2004; Charach et al. 2006). Many describe the decision to medicate as akin to being caught in a web of dilemmas (Hansen and Hansen 2006; Taylor et al. 2006).

Ambiguities and confusions, 11 studies reported, persist past the decision to use medication. The process starts with a trial and error phase as the right dosage might be challenging to determine and parents increase or lower the dosage until a particular amount is found that "works" for their child (Dennis et al. 2008). This phase might be followed by perceived general positive medication effects (Hansen and Hansen 2006; Perry et al. 2005) as children under medication become calmer in class and their concentration improves (Cohen 2006). With poor school grades usually the main reason for seeking professional help (Arcia et al. 2004), most parents emphasize improved academic performance as an important positive medication effect (Arcia and Fernández 1998; Bussing and Gary 2001; Charach et al. 2006; Cohen 2006; Taylor et al. 2006; Wilcox et al. 2007). Some parents note increased self-esteem (Cohen 2006; DosReis et al. 2003) and decreased aggressiveness (Cohen 2006). Others report that parenting stress decreased, or peace of mind increased (Perry et al. 2005). Parents know the positive effects of medications primarily through teachers' reports (Arcia and Fernández 1998, p. 345) because many give medication only during school days, withholding it during evenings and summers (Arcia and Fernández 1998; Bussing and Gary 2001; Hansen and Hansen 2006; Jackson and Peters 2008; Taylor et al. 2006).

Parents also recount negative effects such as loss of appetite, stomach aches, sleep problems (Charach et al. 2006; Hansen and Hansen 2006), sore eyes, obvious twitches (Charach et al. 2006), a "zombie effect" (Jackson and Peters 2008), and increased hyperactivity in the classroom if the child misses a dose (Cohen 2006). These negative effects, however, are tolerated in light of present and future academic objectives for their child (Hansen and Hansen 2006).

Discussion

The limitations of this review include a search strategy for identifying studies from only five bibliographic databases and limited manual citation searching. Dissertations were excluded and other relevant publications could have been missed. Only one author extracted the findings related to parents' concerns, and the studies' authors were not contacted to check the accuracy of our summaries. The data extraction of parents' comments only noted the presence of particular themes in the reports' findings. Given the absence of random or population-based sampling of participants in these studies, we did not attempt to determine whether specific views represented "majority opinions" of the participants, but an effort was made to capture the researchers' own emphases in our summaries.

Parents' concerns—if results are taken at face validity—swirl around their child's academic performance, their perceptions of being blamed by authority figures and society, elevated stress of family life, and battles with the health care and school systems. Their child's poor academic performance appears as the trigger to evaluate, diagnose, and seek treatment. Challenges with homework are reported as one of the two most difficult aspects of living with an ADHD child, and improvement of grades at school is the key measure of the effectiveness of medications and the reason to tolerate medications' side effects. Parents' reactions to their children's actual behaviors vary from study to study (where one occasionally reads that parents commonly cannot distinguish between supposedly normal and abnormal (ADHD) behaviors), yet the same studies report quite consistent accounts from parents regarding troubles with academic performance. Furthermore, parents typically administer medications only during school days, which points to the priority of poor academic performance over other ADHD-like behaviors. Even parents' perceptions that authority figures blame them for their children's behaviors seem tied to the academic performance issue, as these perceptions set in once a child's school performance falters and parents are made aware by teachers. Evidence discordant with this last observation, however, appears in parents' reports that they feel blamed both before and after the ADHD diagnosis. Initially, they felt blamed by teachers and doctors for their children's disruptive behaviors, and in environments including family and public spaces. Once they started medicating their children after the diagnosis, parents felt that friends, family, and media were judging them negatively for resorting to medication. The popularity of opposing views on ADHD and its treatment puts parents in a bind regardless of how they approach the problem.

These findings related to academic performance provide some explanation of why the ADHD definitional controversy endures. Is ADHD merely a label describing disruptive children whose academic performance is lower than expected by adults around them, or is it a bona fide disorder that may or may not affect children's academic performances? Findings from this review suggest that only a thin line distinguishes academic performance problems from being diagnosed and treated for ADHD. Some physicians admit that schools pressure them to prescribe medications (Cohen 2006), which further blurs this dividing line. Neglecting to examine the boundary, and why some children fall on one rather than another side of it, might only serve to perpetuate the use of performance-enhancing drugs,

preceded by a medical diagnosis, as a remedy for children's poor grades. In this respect, only a few studies (conducted by researchers who did not accept a unitary definition of ADHD) elicited accounts from parents on the role of teachers in the process of medicalization, on whether the availability of medication drives diagnosis or vice versa, on how children are actually diagnosed by clinicians, and on the limited alternatives offered to parents as solutions. Moreover, with few exceptions, researchers who defined ADHD as a valid disorder wondered how to bring parents nearer to a biomedical understanding of the problem. Additionally, the more open researchers were to acknowledging the ADHD controversy, the more likely they were to consider broader and alternative viewpoints about these parents' situations and solutions to their problem besides that of dealing with an unfortunate medical condition remedied primarily by the use of prescription medication.

That most researchers are affiliated with health-care disciplines is one characteristic of this body of literature. Of note, mostly women researchers contributed to these studies, suggesting that knowledge on parents of ADHD children is written by women-authors on women-mothers of ADHD children. Moreover, the studies rely almost exclusively on inductive reasoning, because of the advantage of qualitative inquiries in capturing personal accounts. But it limits the construction of knowledge on a specific topic that could be accomplished by using both inductive and deductive reasoning. The near absence of control groups prevents making confident statements concerning the uniqueness of ADHD parents' situations, which presumably lies behind the purpose of investigating them from parents' perspectives. Convenience sampling also limits generalization (Eastbrooks et al. 1994) and might have resulted in the small proportion of fathers in these studies. Overall, this body of knowledge might reflect "insider doctrine" (Merton 1972)—one that can reveal details otherwise missed by outsiders, but vulnerable to concerns about its objectivity; insiders' knowledge may blind researchers to aspects of their topic that they have not taken into account.

This leads us to the observation that fewer than one third of the reviewed studies present theoretical perspectives. The textured nature of qualitative studies allowing for multiple interpretations, it seems crucial that researchers define their theoretical perspective (Shek et al., 2005). Although this view is not uncontested, especially when the researched problem relates to finding ways to intervene with a particular population (Thyer, 2001), specifying a driving theory is considered crucial for the continuance of science as a fallibilist enterprise resting on attempts to falsify existing theories (Gomory 2001) and for increasing researchers' objectivity (Meyrick, 2006). In this body of literature, most of those who recognize the existence of the controversy over ADHD and all of those who define ADHD as questionable construct, also state a theoretical perspective. In contrast, researchers who establish ADHD as a valid disorder state none. This conspicuous difference might superficially reflect the disciplinary backgrounds of the researchers, with medical and nursing disciplines whose practical concerns center on treating children largely ignoring theory, and social science researchers, more or less at the margin of treatment provision, using theory. The difference also raises possibly pertinent questions that must presently remain speculative: Does explicitly entertaining a theory lead an author to reconsider the idea that ADHD is a disorder? Or does an

author include a theory to justify pre-existing doubts on the ADHD construct? Conversely, does the choice to avoid theory narrow some researchers' vision, such that they skip alternative constructions of the nature of ADHD? Put yet another way, does accepting the validity of ADHD narrow the range of research questions such that the corresponding need to explore them theoretically is also narrowed?

Because parents of ADHD children obviously live in the middle of a controversy regarding ADHD and its management, a controversy that might be expected to disturb laypersons at least as much as experts, we think that it should have been recognized by all researchers in this body of work. The controversy of medicating school children with stimulants dates back since the 1970s (Mayes and Rafalovitch 2007), to Peter Schrag and Diane Divorky's *The Myth of the Hyperactive Child* (1975) and Peter Conrad's (1975) article on the medicalization of hyperactivity. Yet in these reviewed studies published between 1996 and 2008, it is incidentally mentioned once in 1998, acknowledged in two studies in 2001, and peaks between 2004 and 2007. If researchers were unaware of the controversy before beginning their investigations—a remote possibility—they evidently encountered it in parents' accounts. Thus, even within the prevalent biomedical framework of this literature, the absence of recognition or acknowledgment of the controversy in two-thirds of the studies becomes a curiosity. In fact, viewing childhood behaviors through medical lenses narrows our ability to consider alternative explanations and can even contribute in depersonalization of children (Graham 2010, p. 8). Meanwhile, acknowledging the existence of a controversy need not imply a stance of the researcher on the controversy, as the researchers' varying definitions of the ADHD construct attest; but failing to acknowledge it establishes ADHD as a valid disorder "by omission" and disregards a dimension of social reality which bears directly on the object of their investigations, parents' subjective views of their child's ADHD.

This literature brings to light another issue: that of understanding parents of ADHD children from different cultures. How culture and ethnicity might influence parents' decisions was examined only by researchers who consider ADHD as a valid disorder, are mainly affiliated with biomedicine, and state no theoretical perspective. Within Western, post-industrial, English-speaking nations, these researchers attempt to understand why parents from minority cultures or ethnicities are not medicating their children who qualify for a diagnosis of ADHD made according to the prevailing psychiatric classification system in these nations. With one exception (Wilcox et al. 2007), the underlying assumption is, understandably, that minority cultures and ethnicities have a model of ADHD-like behavior that differs from the valid one. Yet the assumption seems naïve, given a widespread awareness that depictions of psychiatric symptoms and their assumed causes stem from combinations of cultural influences, historical developments, and political negotiations (Kleinman 1988)—with the diagnosis of ADHD often held up as the exemplary illustration (DeGrandpre 2000). Our review suggests that examining how ADHD-like behaviors are viewed in different cultures might help to understand what, if anything, ADHD is. Future research might benefit from looking at parents without aiming to "fix" their "peculiar" understanding of problematic child behaviors but rather to better describe parents' conceptualization of these behaviors and how it relates to wider features of family, educational, social and economic life.

Finally, in this body of literature on parents of ADHD children, understanding why some parents do not medicate their children appears as a primary concern. Several problem statements express researchers' desires to explore how these parents' reluctance to medicate might be traceable to their culture, their ethnicity, their lack of knowledge or resources, their fear of stigma, or their troubled relations with teachers and doctors. We believe that this line of reasoning serves to shield the biomedical perspective on ADHD from sustained critical analysis. Empirical research conducted with parents of ADHD children has yet to inquire why many parents medicate their children. Exploring reasons behind the use of medications should be as valuable in constructing knowledge about ADHD and family life as exploring reasons behind the avoidance of medications. We suggest that studies that accept the reigning definition of ADHD as a disorder, rather than putting to use the enduring ADHD controversy to maintain a critical attitude toward this key construct, might limit one's understanding of parents' problems with their ADHD-diagnosed children, narrow the relevance of findings from parental studies, and impede the discovery and application of alternative solutions to ADHD-diagnosed children's difficulties.

Conclusion

Parents of children diagnosed with ADHD seem to occupy an uncomfortable controversial position. Although their primary concerns relate to their child's academic performance, they find difficulties in handling the health care and education systems, as well as their own social environment. Also researchers, who have focused on parents of ADHD diagnosed children, have failed to question their own biomedical view of ADHD despite the historical evidence or parents' own accounts. Therefore, this body of literature lacks a thorough understanding of the problem of ADHD, mostly follows a biomedical framework, leaves aside cultural implications, and fails to look further on reasons why some parents medicate their children. So, the knowledge collected about these parents' situations is limited, primarily because of the perspectives embodied by researchers who designed these studies.

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