**THE DECISIONS REGARDING ADHD MANAGEMENT (DRAMa) STUDY: UNCERTAINTIES AND
COMPLEXITIES IN ASSESSMENT, DIAGNOSIS AND TREATMENT, FROM THE CLINICIAN'S POINT
OF VIEW.**

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Abstract

Background: Clinical decision making is influenced by a range of factors and constitutes an inherently complex task. Here we present results from the Decisions Regarding ADHD Management (DRAMa) study in which we undertook a thematic analysis of clinicians' experiences and attitudes to assessment, diagnosis and treatment of ADHD.

Methods: Fifty prescribing child psychiatrists and paediatricians from Belgium and the UK took part in semi-structured interviews about their decisions regarding the assessment, diagnosis and treatment of ADHD. Interviews were transcribed and processed using thematic analysis and the principles of grounded theory.

Results: Clinicians described the assessment and diagnostic process as inherently complicated and requiring time and experience to piece together the accounts of children made by multiple sources and through the use of varying information gathering techniques. Treatment decisions were viewed as a shared process between families, children, and the clinician. Published guidelines were viewed as vague, and few clinicians spoke about the use of symptom thresholds or specific impairment criteria. Furthermore, systematic or operationalised criteria to assess treatment outcomes were rarely used.

Conclusions: Decision making in ADHD is regarded as a complicated, time consuming process which requires extensive use of clinical impression, and involves a partnership with parents. Clinicians want to separate biological from environmental causal factors to understand the level of impairment and the subsequent need for a diagnosis of ADHD. Clinical guidelines would benefit from revisions to take into account the real world complexities of clinical decision making for ADHD.

Keywords: ADHD; clinical decision making, prescribing, medication, clinical guidelines, diagnosis

Attention Deficit/Hyperactivity Disorder (ADHD) is an early onset neuro-developmental condition which often persists across the life span. At its core is a persistent and pervasive pattern of inattention, overactivity and impulsiveness (1,2). ADHD often overlaps with other disorders (e.g., conduct disorder, anxiety, dyslexia; (3,4,5) and is associated with significant impairment across functional domains and in quality of life (e.g., home, school, work) (6). Children with ADHD are more likely to fail at school and go on to be unemployed, to be delinquent and involved in crime, to have substance abuse disorder and other mental health problems (7), and to have problematic family circumstances (7). Moreover, a 2007 study looking at the economic impact of childhood and adolescent ADHD in the U.S. estimated the annual cost of ADHD to be between \$12,005 and \$17,458 for each diagnosed child, with an average yearly cost of \$42.5 billion to society as a whole (8). Taken together, ADHD has a negative impact on patients, their families, and society, and is associated with economic and social, educational, and health care burden. Given these costs, effective management of ADHD is a significant health policy goal (8); however this requires accurate, reliable and valid diagnosis of the condition and the use of appropriate and proven treatment options. When making decisions to diagnose or treat patients, the literature suggests that clinicians are influenced by both clinical and non-clinical factors such as the potential cost of treatment and the patient's social-economic status (9-12).

To assist clinicians and reduce inter-individual variability in practice, evidence-based clinical guidelines provide recommendations pertaining to diagnosis, assessment and treatment for ADHD (13-16). These highlight the importance of the use of psychological interventions especially in milder cases (e.g., psychoeducation, parent training, behavioural management, CBT) and/or pharmacological preparations in more severe cases. However, there is evidence to suggest that clinical guidelines have little effect on changing clinicians' behaviour (17). Barriers to following clinical guidelines include the awareness and familiarity of the guidelines, disagreement with the guidelines, and external factors which are patient related (i.e. patient preference; the patient does not agree with the recommended guideline or treatment) or environmental factors (e.g., lack of resources or facilities) (17). Moreover, in other medical conditions, guidelines are criticised for not adequately addressing the issues relevant to every-day patient care and focusing too heavily on randomised controlled trials (18). A further barrier to implementation of guidelines arises from the fact that the key recommendations of the guidelines are often poorly operationalized, which may lead to difficulty translating the directives into clinical practice. These problems are compounded in the field of child psychiatry because of a lack of an objective diagnostic test and consequent reliance on inherently subjective information about patients' behaviour from different sources such as parents, the child/young person and teachers. In a recent study, Bhugra and colleagues (19) interviewed 31 psychiatrists on their approaches to practice and found that the clinicians in their study described the process of making clinical decisions as inherently complex. Interestingly, psychiatrists

reported relying heavily on intuition to reach clinical decisions, and showed little awareness of potential bias and error in their practice. The authors embedded their findings in the dual process model of decision making (20) in which clinicians use an experience or intuition based approach if the presenting problem is familiar, and an analytical or empirical approach if the presenting problem is unfamiliar or uncertain. Given the paucity of information of how experienced child psychiatrists and paediatricians make decisions specifically for children with ADHD, the aim of the current study was to use inductive qualitative methods to explore the ways in which clinicians make decisions about the diagnosis and treatment of ADHD (age range 5-18 years). Qualitative methods are particularly well suited to gaining knowledge in areas of healthcare that are poorly understood (21,22). Through interviewing a purposeful sample of experts in the field (23), we sought to develop and expand our understanding of the processes underlying clinical decision in paediatric ADHD.

METHODS

Participants

Participants were selected from professional register lists of senior level clinicians working within two distinct geographical areas to get a wide sample of different practices within two major European countries. Only clinicians who had completed consultant-level training were contacted and subsequently recruited and those not diagnosing ADHD were excluded. In the South of England, all of the participants on the Wessex local professional register list were contacted via email (N= 79 psychiatrists and 49 paediatricians) and invited to participate in the research study. In Belgium, potential participants were randomly selected from lists of all of the clinicians working within Flanders (N = 187 child psychiatrists and 793 paediatricians and neuro-paediatricians). From this list, 35 psychiatrists and 114 paediatricians and neuro-paediatricians in Flanders, Belgium were sent a recruitment letter containing the study details.

The main difference between Belgian and UK practice is that in the UK families need a GP referral in order to consult a specialist whereas in Belgium they do not necessarily have to be referred by a GP. Our sampling strategy was designed to recruit 50 clinicians who diagnose and treat paediatric ADHD from these two different professional bodies to represent the full variety of possible approaches to clinical decision making with regards to ADHD. Consequently we attempted to recruit and interview roughly equivalent numbers of both child psychiatrists and (neuro) paediatricians, physicians with different career lengths, working in different mental health or child health systems in the two different countries.

This paper therefore reports the views and experiences of 50 clinicians. Participants consisted of 21 males and 29 females. Participants from Belgium (n=28) included 15 psychiatrists and 13 paediatricians and paediatric neurologists. UK participants (n= 22) consisted of 13 psychiatrists and 9 paediatricians. Participants' length of experience in independent consultant level practice across both countries ranged from 1 to 37 years. For confidentiality, participants were ascribed unique identifiers. These consisted of a letter referring to the country that the interview took place in (E = England; B = Belgium) and a number.

Procedure

The semi-structured interview was developed in collaboration with two senior consultant psychiatrists (authors MD and MT) to explore themes around clinical decision making. Open-ended questions were designed around the study's research aims and allowed the clinicians to talk freely from their own perspectives about how they gathered information upon referral of a case and how they reached decisions about assessment and diagnosis. To reduce positive reporting bias and increase the validity of the findings, clinicians were asked to talk through how they had assessed and diagnosed recent cases they had seen in the clinic. We also explored how these factors impacted upon decisions regarding treatment initiation, switching, and discontinuation. Participants were informed that the aim of the study was to explore the variety of different approaches that clinicians use when making decisions about behavioural problems by hearing their individual experiences, perspectives and opinions. The interview and study protocol received approval from University and Medical Research Ethics Committees. (The full interview schedule is available from the first/corresponding author).

Interviews were conducted by doctoral level researchers (authors HK and MV) who had been trained to conduct qualitative interviews. Interviews typically lasted for one hour and occurred at a time and place that was convenient for participants which was often their place of work. Participants were offered a nominal fee which was paid either to them personally or to their employer. With participants' consent, interviews were tape-recorded and transcribed verbatim. Belgian interviews were conducted in Dutch and the resulting transcripts were then translated by a non-clinical bilingual research assistant into English for analysis. Where there was any doubt about the accuracy of a translation, phrases were double checked by 2 bilingual authors (MD & MV).

Analysis

An inductive approach to thematic analysis (24), enhanced by the principles of grounded theory (25), was used to identify broad themes and sub-themes from the interviews. More specifically data analysis followed an adapted approach to the six-stage process outlined by Braun and Clarke (26). Data was analysed by SW, a post-doctoral

researcher experienced in qualitative analysis and supervised by LY, a leading professor in health psychology and expert in qualitative methods. The first step involved the primary analyst immersing herself in the data by re-reading the transcripts and making notes of early relevant ideas. Second, open codes were generated by identifying and labelling particular features and concepts within the data that were considered important to clinicians, thus staying close to participants' own descriptions. The third stage involved collating all relevant codes together into overarching themes through higher level coding. This was an iterative process moving between the data and themes and splicing and splitting themes to ensure they worked with the data. Constant comparisons, reflexive memo-writing and diagramming were also used to ask questions about the data and explore how the themes and sub-themes fit together and also to explore the interpretations that the researcher brought to the analytic process.

Themes were then reviewed to ensure that they worked with the original transcripts and checked for inter-rater reliability. During this process a detailed coding manual illustrating the definitions and examples of themes was scrutinised by a second researcher and then used with the data (see 24 p.62-63). Inter-rater reliability was tested by an independent coder on all of the themes and sub-themes by reviewing a random sample of 10% of all the excerpts relating to each theme and sub-theme. This suggested agreement with the coding manual on 79.4% of coding decisions. Any differences between the coding were discussed until both coders agreed.

RESULTS

The inductive thematic analysis yielded two overarching processes, Clinical Assessment and Shared Decision Making. Clinical Assessment incorporated three themes; Pieces of the puzzle, Assessing biological and Environmental Factors, and Understanding the impact of the problem. Shared Decision Making consisted of five themes; Tailoring treatment to the individual child, Clinician factors, Factors within the family, Decisions to start or stop treatment, and Evaluating treatment effects (see Figure 1 for the thematic map). While many perspectives were shared between participants, there was considerable heterogeneity in responses as well. Rather than identifying differing perspectives between the two countries, it was found that clinicians held their own individualised views about the management of children with ADHD and these differences of opinion are considered throughout the analysis. Only two main differences between the two countries were observed and these related to practical factors associated with managing ADHD patients. First, Belgian clinicians used psychological testing more frequently during clinical assessment. Second, the structure of Belgian practices meant that they had larger multi-disciplinary teams that enabled them to make decisions within a team setting. Again, these differences are considered in the analysis below. In presenting the themes and sub-themes in this paper we have focused on those elements which have the most clinical resonance, both empirically (i.e., the most frequently discussed concepts and processes), and clinically (i.e., perhaps less frequently

cited but clinically salient). We have provided percentages of how many participants volunteered a specific idea or practice. As we used an inductive approach, these figures cannot be used to quantify the proportion of individuals who held a view or would have endorsed it if asked. However, we provide this number for illustrative purposes only, as an indication of the prevalence of the expression of particular views in our sample. A list of all of the themes and sub-themes are available from the first/corresponding author.

Insert Figure 1 about here

D) Clinical assessment: Clinicians talked about being faced with the complicated task of collecting and piecing together the histories and accounts of the children and their parents whom they see in their clinics. Most of the clinicians stressed the importance of a detailed clinical assessment and the need for multiple sources of information. Assessments for ADHD included obtaining subjective and objective information such as: first-hand accounts from parents, schools, children, other care-givers or health professionals as well as information from their own clinical impression, direct observation of children (at school or in the consultation) and through self-report questionnaires or psychological tests. This breadth of information gathering was discussed as a key component of the assessment process to gain multiple views of the child from different perspectives.

1) Pieces of the Puzzle. Twenty six percent of clinicians in the study referred to the process of gathering information about the child's condition as assembling "*pieces of the puzzle*" (B1). This involved looking at the "broad", "overall picture" of the child's situation and bringing all of the "pieces of the puzzle" together to find a "leading thread" or "hypothesis" that could best explain the situation. Clinicians therefore said that it was important to collect information from many different sources and over a number of consultations to ensure that the full picture of a child's situation could be brought together, and that the assessment was not biased towards only one or two sources.

Discrepancies between sources and accounts of the child were described as being commonplace, perhaps simply because different impairments appear in separate areas of a child's life. Nevertheless, clinicians described a number of strategies that they used to try and resolve competing accounts of the child during the assessment process. This included ranking the sources of information received, for example from parents and teachers. The reporting source that received the greatest weight was determined by a range of factors including the family situation (e.g., were parents in disagreement about the child or in the process of a divorce), as well as the clinicians' relationship and

knowledge of the school the child attends. Some clinicians spoke of teachers as the more experienced judges of typical and atypical behaviour based on their experiences of multiple children in different settings.

“I always trust the teacher more, unfortunately. There are many reasons for this. Teachers spend much more time with children than parents. Second, teachers have got much wider experience with different children....teachers seeing fifty or thirty children in the classroom can easier pick up abnormal behaviour and the evidence of the teacher is more valuable for me always.” (E21).

When parents disagreed in the information presented about their child, several clinicians said that they try to resolve discrepancies by obtaining observational data directly from schools or from other school-based professionals (e.g., educational psychologists, school nurses). They also used their own experiences of the child in the clinic to help resolve inconsistencies, though many recognised that this setting was somewhat artificial and that behaviour there may not be representative.

To ensure that detailed information was collected before issuing a diagnosis, clinicians (44%) stressed that the assessment period may take a long time. Many of these clinicians also said that if a child had clear difficulties alongside other problematic events (e.g., the child was being excluded from school or was in trouble with the law), the assessment period might be shorter. However, 36% of clinicians also talked about taking a history from the child or specifically asking the child to describe their presenting problems and experiences at home or school. The type of information gathered varied greatly between clinicians as some preferred the use of standardised measures, while others employed a more eclectic approach based on clinical interpretation. In discussing the usefulness of standardised assessment versus clinical observations, one participant said:

“There is not a kind of a standard assessment that I regard as adequate. I suppose I’m relying on my 10 years experience to pick [up] on risks and stuff that a fully comprehensive assessment would expect to go into all areas I would expect to come up in the style of conversations I employ.” (E13)

Reliance on multiple sources of information and subjective clinical impression in order to formulate a diagnosis was often described as difficult and frustrating for clinicians.

“[...] there are no absolutely clear tests. To me, that’s the most frustrating thing – that it’s actually a lot of speculation and it’s so multifaceted really.” (B25)

2) Assessing biological and environmental factors. This theme reflects the process of disentangling the source of behavioural issues and the often difficult task of determining whether symptoms or behaviours may be explained by biological or environmental factors, or an interaction between the two. A child’s behaviour could therefore have

multiple explanations, and 72% of clinicians often looked for other reasons for the behaviour prior to deciding that the child might have ADHD. Sixty two percent of clinicians said that they assessed the family situation and parenting factors and appeared to believe that presumed environmental ‘causes’ such as negative school experiences, relationship problems, a chaotic family background, or a history of child abuse or neglect may preclude an ADHD diagnosis.

“Sometimes you have situations where you have a lot of difficulties in the family level, or in the broader context that can provoke the ADHD-like behaviour. For example a divorce and a mother who has very little time for the child, a child who is actually depressed about it, and a result of that [the child] could have ADHD-like symptoms.” (B2)

Clinicians described the importance of taking a careful developmental history (n=24) to identify these and other environmental ‘causes’ which they believed may masquerade as ADHD, or provide evidence that ADHD has been present from an early age. Despite there being no guidelines to support this practice, family history was also described by 28% of the sample as a vital factor as it may reveal genetic liability to ADHD:

“Nowadays there is greater awareness I think of ADHD in the population because it is such a heavily genetically determined condition. There are often several other [diagnosed] members of the family and so there’s a personal experience in many cases. You’re not going on virgin territory really... I think the actual family and personal history is vital to be recorded and put down.” (E12)

Clinicians (44%) reported that the majority of cases seen in the clinic were ‘complex’ with ADHD symptoms presenting alongside symptoms of other conditions. These included somatic diagnoses including hearing difficulties, pulmonary problems (e.g., asthma), sleep disturbances, epilepsy, and other developmental or psychiatric diagnoses including autism spectrum conditions, bipolar or anxiety disorders, and/or general developmental delay. For example, B24 described a:

“[...]complex case where several hypotheses and diagnoses fit. I think that the boy really had a cluster of problems, with deficits in his capabilities and abilities as well as what was happening in his environment.”

Consequently, 38% of clinicians reported being faced with dilemmas of whether to make a separate diagnosis of ADHD alongside a previously diagnosed condition. In these cases, 16% of clinicians described collaborating with or referring patients onto other clinicians or multidisciplinary teams. Despite the lack of empirical evidence to suggest that a trial with medication would assist in making a diagnosis, another approach to uncertainty used by one fifth of the

sample (20%) involved experimenting with medication to see whether this could help confirm the correct diagnosis.

As B8 revealed:

“[...] it still happens and I know its not allowed - trial therapy...I think there is nothing against trying Ritalin for a month, possibly without telling the school...I have been able to classify a few [cases] like that.” (B8)

More generally however, clinicians concurred that medicating early was not recommended and as participant B25 explains, this can actually be problematic:

“A trial therapy with Ritalin doesn’t discriminate between the children who do need it and children who don’t really need it.” (B25)

3) Understanding the impact of the problem: When weighing up the number of symptoms and level of impact they had on the child’s functioning, clinicians wanted to know how symptoms were affecting the child in various domains. Many stated that the effect or burden that symptoms had on the child, their parents and other family members would influence their diagnostic decisions.

Internal domains of impact on the child described by 48% of clinicians included the child’s happiness, self esteem, or perceived level of suffering, and external domains of impact included academic success, peer relationships and trouble at school or with the law. The impact of the child’s symptoms on the family was taken into account by 52% of clinicians, particularly when parents gave descriptions of struggling to cope or manage behaviour.

“Mum was absolutely at the end of her tether and wanted something because she jus(t) said ‘I can’t cope, I’m going to have a breakdown basically, and so we talked through the ADHD”(E3)

II) Collaborative decision making about diagnosis and management. It was clear from clinicians’ descriptions that they made significant efforts to include families in the decision making process. Consequently, a treatment approach which was tailored to the individual child and family expectations and/or viewpoints was seen as essential. Collaborative decision making was described as an iterative, cyclical process and thus involved a complex interplay between factors intrinsic to the child (tailoring treatment to the individual), the clinician’s recommendations (clinician factors), and the beliefs and expectations of the family (factors within the family). These themes will now be considered in more detail.

4) Tailoring of pharmacological treatment to the individual child. Clinicians talked about tailoring treatment targets to the individual and the areas of impact upon the individual child’s life. Only 8% of clinicians described using symptom reduction in isolation as a pure treatment goal, and instead spoke about focusing on improving the child’s

chances of success in multiple domains including academic, familial, and social areas. Other factors which 22% of clinicians described as determining treatment goals included safety issues, particularly in cases where children were perceived to be a danger to themselves or others or if the child was in trouble with the law. When cases were perceived to be less severe, 18% of clinicians talked about using a ‘wait and see’ approach.

Treatment decisions were described as being dependent on on a number of child factors including their weight (14%) and the need to monitor cases of significant weight loss, as well as age (56%) (stimulant medication is not licensed for children under the age of 6 with the exception of dexamphetamine in the UK).

“Yes, he was coming up five... it was about a year that we were sort of keeping an eye [on him], in terms of was [the situation] going to deteriorate really rapidly, you know how are they managing it really. It wasn’t fantastic but neither was it a complete disaster; you know if he was going to a different school at the time, it might have meant that I would prescribe, you know, get my arm twisted to prescribe off-licence.” (E14)

Adolescents in particular were described as needing to be included in the decision making process, and were most often prescribed long acting formulations that could be taken in the morning and last the full day to avoid the stigma of needing to take medication throughout the day. Furthermore, a certain amount of tailoring treatment was discussed as a function of the child’s comorbidities (e.g., epilepsy or tics) or other symptoms (36%).

I also had one [child] where we were going to start Strattera, because the child also seemed to hear voices and to have imaginary friends. And I thought Ritalin wasn’t such a good choice to immediately start with. (B28)

5) Clinician Factors. Clinicians’ personal perspectives and viewpoints of diagnosis and treatment were a clear factor in striking a balance between reports of the child from various sources, findings from their own assessments and the wishes of the child and family. While some clinicians worked within teams and made diagnostic and treatment decisions in parallel with colleagues, others worked individually. In cases where clinicians worked independently (more frequently in the UK than in Belgium), the potential for personal viewpoints to disproportionately influence practice appeared to be greater.

“I personally believe that ADHD is over-diagnosed in many children. I know a few years ago I wasn’t believing [sic] in this diagnosis at all. That’s my personal belief [...] my personal impression is that many so-called ADHD cases are simply stress related and poor children are responding with this behaviour to the stress and to the family problems. But of course they fulfil the criteria because they respond to the stress at school and at home and they cannot deal with this stress and they cannot cope and they are inattentive and hyperactive and diagnosed with ADHD.” (E21)

Only 46% of clinicians talked about their difficulties in using diagnostic labels and they had different perspectives on how diagnostic labels should be used. They also had thoughts on the implications of labelling. In particular, clinicians expressed caution about using labels to categorise children or mentioned cases in which they would have preferred to treat children medically without imparting a label upon them:

“I’m not really in favour of making diagnoses. That’s to say, to put stamps, I shall say it like that. Actually I mainly do it with the view of getting help.” (B9)

Views also varied between clinicians around the use of diagnostic criteria; most described an individualised approach which relied to a great degree on their clinical judgement and experience, while only 10% of clinicians described a very clear and focused process which relied on explicit objective criteria.

“[...] idiosyncratic practice developed by me over the years really. I’m mindful of medicine, NICE guidelines, types of practices, medical model approaches. I’m mindful that anybody coming in and saying Dr [name] was a complete charlatan might look at the work I do, and I would have a higher than average job to do to justify why I was doing it this way rather than you know, taking a full history that covered all these different domains and making sure that I got a questionnaire filled in. I need to go the extra mile to justify why I think that and I think I can.” (E13)

Similarly, only 14% of participants mentioned that they consciously adhered to published clinical practice guidelines (NICE, 17 and SIGN, 16) and none of the participants mentioned the European guidelines. When mentioned, views about the guidelines often focused on questioning the ultimate place and practicality of guidelines in the clinical setting.

“[...] it boils down to it that every person is an individual person, and you can’t use a guideline in our profession. I’m absolutely against that. That doesn’t work.” (B11)

6) Factors within the family (family’s views on ADHD and treatment).

Clinicians reported balancing their own beliefs and views with what they have learned about the child and the family’s wishes, as well as more systemic factors such as what they understand about the family’s functioning as a unit and their available networks or support systems. Fifty two percent of clinicians in our study spoke about the need to tailor feedback appropriately to the family. They explained that on the one hand, an ADHD diagnosis could open up opportunities for further management of the child’s problems through gaining access to support or medication. However, in some circumstances, they felt that a diagnostic label could also have the opposite effect of preventing the most effective management for the child:

“You’ve got to weigh up whether giving the label is a positive thing or a negative thing and whether if you give the label you’re actually going to prevent anything else from happening because therefore you’ll get a very blinkered response and that would be a negative about making the diagnosis.” (E14)

Clinicians spoke about other situations where they felt that giving a diagnostic label may impede any potential efforts by the family to work on wider parenting or other familial factors that also play a part in affecting the child. They felt that using a diagnostic label may establish the problem within a biomedical-only explanation of the child’s behaviours resulting in wider psychosocial factors being overlooked. They described a dilemma between reassuring parents who “blame” themselves for their child’s difficulties whilst not simultaneously conveying what was viewed as an erroneous message that the parent is therefore absolved of any responsibility to help the psychosocial environment for the child. Accordingly, situations were described by 38% of clinicians where families were reluctant to work on wider psychological factors, instead only wanting medical intervention for their child’s ADHD.

“Some parents are just really not interested. They want the drugs – and I think it’s quite a difficult situation because, ok, yes, there is a diagnosis; everything fits together. Yes, it’s appropriate to trial medication – but are they going to treat this sensibly? Do I have informed consent? Do they really know they are giving a powerful controlled drug to their child? That is a concern.” (E19)

Other families were described by 44% of the sample as rejecting the ADHD label and the medicalisation of their child’s behaviours.

“It is very difficult to give feedback sometimes if parents don’t want to hear about the possibility of ADHD; it’s not always a cool diagnosis. I’ve certainly heard one comment along the lines of we come from a nice family - that doesn’t happen in our family he’s just a bad boy and the problem has really been not wanting that label”. (E3)

In these instances, clinicians spoke about the need to carefully balance the family’s views with what he or she believed to be in the best interest of the child. The role of the clinician seemed to become in this situation one which helped to steer the family towards treatment options that would ensure that everyone was acting in the best interest of the child.

“I saw a mum who indeed has a negative attitude towards medication but was kind of put under pressure by the school. [The medication] was started then. He really did better with it but mum continued to question it. And I felt like ‘Should I maybe stop [prescribing] for a while?’ to validate the feelings of the mother...to give it a chance to see how he does without medication.” (B15)

In keeping with this, 76% of clinicians agreed that families needed to be on board with whatever treatment options were prescribed and that prescribing medication when the family was against it was futile as parents need to source and administer medication in young children.

“I regularly have people about the house who are opposed to medication and who want to try omega-3 fatty acids first or a sugarfree diet or no colouring agents, or who want to go to a homoeopath or an acupuncturist. And then I usually let them do that first. Because that is the sign that they are not ready for medication.” (B28)

Overall, the final decision about how to manage the child’s ADHD was seen by 28% of the sample to be made by the family, taking the clinician’s recommendations into account.

“You’ve got a dilemma - do the risks outweigh the benefits if you do [prescribe] but to me that’s the parents’ dilemma. I simply have to decide whether this kid is prescribable - they have to decide whether to give it to their children. I weigh up the pros and cons.” (E13)

7) Evaluating treatment effects. Clinicians described children’s response to treatment as characteristically dependant on a range of factors including their weight, age, and environmental demands or expectations. Thirty-six percent of clinicians described “a dilemma” between balancing the lessening of ADHD symptoms against the tolerability of side effects when monitoring the effects of stimulant medication.

“When measuring height, weight, and blood pressure, (for) some [children] you see that height is not increasing as it should be. Perhaps for this child, the medication is very effective. So you are in a dilemma whether to stop the psychostimulant altogether or start another medication like atomoxetine which does not affect growth as much as stimulants. But, you are not sure whether that will work and needs to be built up. Or, do you continue on stimulants with a smaller dose, or change the type of food, the time of meals, work around diet and food. So you are not certain what you are doing until you decide on one or the other.” (E18)

Clinicians revealed a range of methods used to evaluate treatment effects which varied between very narrow and unsystematic to more comprehensive and systematic approaches. Several collected feedback about the child’s well being and current level of functioning from multiple sources including parents (52%), schools (50%) and the child themselves (34%), particularly as they got older. Sixteen percent of clinicians also used questionnaire measures to gain a more objective picture of the child, or to compare the findings against those collected during the diagnostic phase. Others simply monitored physical factors (e.g., weight and side effects) and spoke with the parent and child to see if they perceived there to be recent improvement in symptoms or behaviours. They talked about trying to gain

information regarding improvement by asking pointed questions about academic performance, social acceptance or whether the child is making academic improvement.

“[I ask whether he] is invited to birthday parties. If he’s not invited anywhere that’s usually not a good sign. Often, if he’s improving, you hear that he’s invited again, that he’s welcome. Parents say ‘he’s a nice boy, he’s doing fine’.” (B13)

Forty percent of clinicians also measured treatment effects by asking parents and children to compare moments when the child was on and off medication (e.g., evenings, weekends, missed doses, or drug holidays).

“[...] you don’t actually say ‘do you take your medication every day’. My standard question is “when you forget to take your tablets, what do you notice?” It’s a good way of [discovering] whether they still benefit from the medication or whether they need to alter it in anyway.” (E12)

DISCUSSION

This study is believed to be the first of its kind to use inductive qualitative methods and semi-structured interviews to investigate the clinical decision making of clinicians who diagnose and treat children with ADHD in Europe. While clinicians in our study practised in two different European countries, the South of England and Flanders in Belgium, the descriptions of their work with children with ADHD reflected many similarities in practice. The main difference between the two countries, namely that patients in Belgium can self-refer to senior consultant level clinicians while those in the UK require GP referral, did not seem to be reflected by differences in the way in which clinicians make diagnostic or treatment decisions.

Qualitative methodology allowed us to focus on participants’ own experiences of a phenomenon and hear their views in their own words. Thus, a qualitative study of clinicians’ experiences avoided the imposition of the researchers’ perspectives and assumptions about clinical decision making in relation to ADHD on the themes derived. In a recent study using qualitative methods to investigate psychiatrists’ clinical decision making, Bhugra and colleagues (19) found that clinicians relied heavily on their experience and intuition in making decisions, particularly if they had greater levels of experience and years in practice. Clinicians also talked about their decisions being influenced by uncontrollable factors including the length of time they had to make a diagnosis which was often dictated by their work setting, the availability and cost of medication, and the varying level of compliance of psychiatric patients (19).

The psychiatrists in Bhugra et al’s (19) study were not posed questions specifically about decision making for childhood psychiatric conditions which may involve different processes. Rafalovich (27) conducted a sociological

study using qualitative methods to explore clinicians' experiences of diagnosis and treatment of ADHD in North America. However, his aim was to identify how clinicians' experiences "*are affected by the well-publicised concern about the validity of ADHD and the chemical means in which the disorder is most commonly treated*" (p. 308). Clinicians expressed 'ambivalence' about diagnosing and treating ADHD in children, reporting uncertainty about the nature of ADHD and exertion of caution when prescribing medication. Clinicians also highlighted the disparity between following diagnostic protocols which may seem comprehensive on paper, and the realities of their own clinical practice. Nevertheless, Rafalovich described the overall aims of the study as discussing the 'concerning' nature of ADHD and its treatment and he therefore took a selective focus on this topic. Our aim was to obtain a more neutral and comprehensive overview of how clinicians assess and/or diagnose a child somehow suspected to have ADHD. Unlike those interviewed by Rafalovich, relatively few clinicians in our study described ambivalence or being 'affected by scepticism' in prescribing stimulant medication, however they echoed the views of those in Rafalovich's study in describing guidelines as vague and lacking validity.

Similarly, when asked about making decisions for ADHD, clinicians in the current study described finding the process extremely challenging. Reasons for this included; (i) the absence of a medical or biological test which would confirm or disprove the existence of ADHD; (ii) reliance on information collected from caregivers, teachers and the child and the inherent subjectivity of these reports; (iii) the need to integrate different and perhaps contradictory perspectives; (iv) the lack of clear and universally accepted and operationalized clinical practice guidelines. Clinicians used very different approaches to tackling these problems; partly due to differing views about assessment and treatment and partly due to variation in resources and settings. For instance, some clinicians had access to multi-disciplinary teams or stricter referral policies. **Whilst the clinicians we interviewed held a range of views and provided heterogeneous responses to our questions, we have attempted to draw across all of the participants to provide a number of key messages from the themes in the results.**

i) A broad focus combined with systematic and careful assessment: When assessing a child, clinicians did not describe using a narrowly focused 'ADHD' protocol but a more general and broad assessment which included ADHD, but only as one amongst a host of hypotheses to be tested. Accordingly, a diagnosis of ADHD may in some cases be made without adhering to strictly defined criteria, systematic use of symptom checklists or symptom counts. Nevertheless, to say that clinicians do not follow a system would also be inaccurate; rather, an approach which allows clinicians to work within a wider framework of possible conditions was described. Most of the clinicians in the current study stressed the importance of taking a full developmental history, including assessing whether there was a family

history of ADHD, and evaluating the family relationships and context. Information from school was more typically collected in a systematic way using formalised reports or questionnaires.

ii) Gestalt/pattern matching/experienced-based approaches to diagnosis rather than standard symptom counts:

Clinicians seemed to gather as much information as possible, then apply implicit pattern matching – forming a gestalt of the available data rather than applying a formal protocol. Other clinicians described an approach consistent with prime salient factor thinking or “looking for a leading thread”, and still others followed parent’s beliefs and interpretations of their child. In doing so many participants drew heavily on their experience of past cases to look for a common thread or pattern which made sense of their data. This was described by some as making decisions based on “gut instinct”. Interestingly, this is consistent with the Bhugra et al (19) study where psychiatrists also described using intuition to make clinical decisions, particularly when they were familiar with the presenting problem. The clinicians in this study were all specialists in childhood ADHD and thus this may explain their use of a more intuitive type of decision making as described in the dual processing model (20). However, it must be noted that clinicians who principally employ an experienced based eclectic approach to diagnosis rather than a more empirically driven systematic approach, introduce bias and pose a threat to the validity of the diagnostic process. One explanation for why highly skilled clinicians tend to use more experienced based approaches is that they may lack either the time to engage in, or access to, continuing professional and educational development. Alternatively, the issue may be that the clinicians deliberately choose not to follow the protocols recommended by published guidelines. While clinical practice guidelines can make suggestions about specifically required inputs to an assessment procedure (e.g., clinical interviews and collection of data from multiple sources), they fail to capture and provide guidance on the interpretation of such data following the lengthy and comprehensive process of clinical assessment and decision making. Consequently, the multifaceted and complicated process described by the clinicians is not fed into a more systematic application of evidence based guidelines for diagnosis and treatment, which could possibly avoid intra-and-inter-individual idiosyncrasy. Revising guidelines to make them more accessible and relevant to clinical practice through providing clear operationalized definitions, and opportunities for professional and educational development in guideline application, would significantly improve the current state of clinical practice of ADHD in paediatric psychiatry.

iii) Looking for reliable information and dealing with discrepancy: Most of the clinicians we interviewed were in agreement that diagnosis cannot be made without collecting detailed information about the child from multiple sources. The integration of these different sources, particularly when the information provided is contradictory, involves complex clinical reasoning and is by no means operationalised or systematic. Clinicians cited many reasons for

discrepant reports of children by different informants. Some of these reasons may be verified, but others are entirely dependent upon the interpretation of the clinician (for example mothers and fathers giving opposing accounts of the child in the home setting, or parents and teachers disagreeing between the nature of the problems of the child). In these cases, not only was there between-clinician variability of who to ‘side with’ or believe, but there was also within-clinician variability dependent on the individual case. While some participants revealed they tended to believe one source more (e.g., teachers for their developmental knowledge or mothers for their historical knowledge), others attempted to uncover the source’s possible biases (e.g., a teacher or parent’s disbelief in the construct of ADHD). This process of uncovering and making judgements about the trustworthiness of different sources, at least for the proportion of clinicians who hold significant biases, may be a factor of inter-clinician variability in diagnostic caseness.

iv) The measurement of impairment is crucial for diagnosis, but it is poorly operationalised: Clinicians regarded impairment as an extremely important component of the clinical picture; in fact sometimes it took precedence over reported symptoms. Several examples of domains of impairment (e.g., lack of family cohesiveness, school failure, low self worth, or generally not meeting their potential in multiple domains) were given as important criteria for diagnosis. Thus, we suggest that the particular domains that are thought to be relevant to the assessment of impairment, and the degree and severity of impairment that is required to reach caseness, is individualised. Moreover, the way that symptoms and impairment are interrelated is likely to be perceived differently by each clinician. Some clinicians gave examples of assessing the impact of each separate symptom and only regarding it as a *relevant* symptom when it is impairing. Others only considered impairment as an *overall* impact of ADHD on the child’s functioning. Others still considered both of these approaches in unison. In this approach, for each separate symptom to count, impairment due to the particular symptom needs to be present.

v) Identifying “true” “biological” ADHD from its pheno-copies: Diagnosis of ADHD is more likely to be made when clinicians believe that symptoms are due to biological or intrinsic neurodevelopmental problems which arise from within the child. ADHD was not described as a behavioural construct which may also result from environmental causes such as maltreatment, learning/educational difficulties, or attachment issues. In so defining ADHD as a medical condition, it is almost used as an exclusionary diagnosis; first all other possible reasons are considered which may explain the presenting symptoms or behaviours. This not only includes somatic differential diagnosis, but also parenting problems and/or maltreatment. In this sense, ADHD was not viewed as a heterogeneous behavioural construct irrespective of underlying causes. Clinicians seemed to have an implicit theory about the ‘true’ causes of ADHD, and ‘false behaviours’ which mimic ADHD or parents try to pass off as ADHD. They pointed to two pieces of information that made them more inclined to believe that the child had ‘true’ ADHD; a family history of ADHD

(which makes a genetic cause more likely) or an early developmental history of ADHD behaviour. This causal reasoning influenced treatment choices such that behaviours linked to child rearing problems were more likely to be referred for family therapy (resources providing), than medication. The cyclical nature of a difficult-to-parent (possibly ADHD) child leading to a negative parent-child relationship was less often explored if the clinician had made a prior judgement that the child's behaviour was a result of 'bad' parenting.

vi) Caution over labelling: The consequences or sequelae of applying an ADHD label to a child were given significant consideration by the clinicians. Clinicians or families may have strong views either in favour or against the use of the ADHD label. As in other domains, there was both inter-individual variance and intra-individual variance, where depending on certain issues, a label may seem favourable in one situation but not another. Thus, deciding whether or not to use the label not only depends on a clinical decision based on applying diagnostic criteria or a clinical impression that the child has ADHD, but also consciously depends on a clinical decision based on the view of whether such a label is in the best interest of the child. Interviewees described instances where specific reflections for individual children or families were made.

vii) The influence of the family: Once a diagnosis is made, decisions around the choice of treatment are tailored to a great extent to the child and the family's wishes. There was a large consensus that this is a collaborative process between the clinician who may offer advice and guidance, and the family who may express their wishes and who ultimately make the final decision. Children were included in the decision making process to a greater degree with increasing age. Accessibility and availability of various forms of treatment (e.g., psychological therapies, or more expensive pharmaceutical preparations), as well as local medication guidelines (e.g., that stimulant medication must be prescribed prior to atomoxetine), also play a role in treatment decisions. It was unclear from our interviews however, how far and how often these factors lead the actual treatment decision away from what is stated to be best clinical practice in the National Institute for Clinical Excellence (NICE) (15), Scottish Intercollegiate Guidelines Network (SIGN) (16), or European guidelines (13,14).

viii) Poorly defined treatment targets and inconsistent monitoring of targets: Defining the targets for change before or during treatment was once more a largely non-systematic and non-operationalised process. Moreover, once some form of treatment was discussed and initiated, the follow-up of treatment was mostly described in quite general, broad terms. Clinicians varied between choosing global well-being versus specific targets, though many lacked detail about which targets were chosen for specific children and why, how these targets are defined and monitored, who decides on targets, and what exactly constitutes change or improvement.

ix) Guidelines are not at the forefront of the diagnostic process: Generally, we found that clinicians rarely explicitly drew upon guidelines or diagnostic criteria. This is not to say that they are not followed; rather, we are suggesting that guidelines do not seem to be at the forefront of clinicians' minds when considering their assessment and treatment decisions for children with ADHD. Implicitly, guidelines may be known and clinicians may have these at the backs of their minds, but at least in our sample, they are not used as their explicit clinical framework or may be judged to ineffectively capture the complexity of clinical practice. Working in accordance with a structured protocol and using guidelines is a way to systematise, standardise, and operationalise assessment and monitoring procedures, and this does not appear to have been taken on board in everyday clinical practice.

Notwithstanding, guidelines were often criticized for their poorly defined concepts and lack of operationalization, which may lead clinicians towards varying interpretations of the same recommendations. Moreover, the frustration conveyed by participants regarding the absence of a precise diagnostic test for ADHD may be a reflection of the difficulty in reaching a clear consensus of how the guidelines should be put into practice. The absence of precise and clearly delineated recommendations for practice mean that current guidelines can be considered theoretical documents that lack grounding, and fail to resound in everyday clinical practice. However, failure to implement published clinical guidelines in clinical practice is not an issue that is specific to psychiatry. Grol (28) analysed data from a database of 7000 physicians, studying the implementation of 70 guidelines, with large variation in practice between different physicians and medical conditions. He found barriers to following guidelines included doubts about the value and scientific grounds of the guidelines, resistance to efforts to motivate patients, clinicians' belief that they created extra workload, desire to follow their own fixed routes, belief that guidelines were too complex or too difficult, and a tendency to give in to inappropriate patient preference to avoid conflict.

Conclusions: This study allowed us to gain a good overall view of the perspectives and issues that clinicians who diagnose and treat childhood ADHD have and allowed us to explore the relationships between different phases of decision making. However, future qualitative research may wish to hone in on particular aspects of decision making for clinicians to further elucidate issues of importance. For example further research into clinicians' experiences of and views about published guidelines, and how guidelines can be improved to reflect the complex nature of clinical practice is needed.

It is important to consider that whilst the findings report the key concerns and understandings of clinicians from their own experiences, they are based on clinicians' descriptions of their own practice and therefore it may be possible that these accounts do not reliably map on to what clinicians actually do in practice. The current study tried to control for this factor by asking clinicians to talk through and describe their clinical decision making using genuine recent cases. Nevertheless, the potential for a reporting bias remains possible. Future research may want to supplement first-person accounts with analyses of clinical case notes or observations of clinicians' casework.

Several factors may influence decision making such as professional training (e.g., psychiatry versus paediatrics), and practice guidelines in various European countries. With these considerations in mind, future research should explore the interrelationship between the use of published guidelines in clinical practice, and how this may be shaping the field of ADHD. These guidelines are not stand-alone documents and must now respond to clinicians and their concerns with updated advice that more accurately captures the real-world complexity of clinical decision making.

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Figure 1