Review

Medication-taking experiences in attention deficit hyperactivity disorder: a systematic review

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Abstract

Background. Although attention deficit hyperactivity disorder (ADHD) is a common condition for which pharmacotherapy is considered an effective treatment, guidelines on the treatment of ADHD have been challenging to implement. Considering the views of patients and caregivers involved in medication-taking could help shed light on these challenges.

Objective. This review combines the findings of individual studies of medication-taking experiences in ADHD in order to guide clinicians to effectively share decisions about treatment.

Methods. Five databases (MEDLINE, Embase, PsycINFO, SCOPUS and CINAHL) were systematically searched for relevant published research articles. Articles were assessed for quality using a Critical Appraisal Skills Programme checklist, and synthesis was performed using meta-ethnography.

Results. Thirty-one articles were included in the final synthesis, comprising studies of caregivers, paediatric patients and adult patients across seven countries. Findings were categorized into five different constructs, including coming to terms with ADHD, anticipated concerns about medication, experiences of the effects of medication, external influences and the development of self-management. The synthesis demonstrates that decisions surrounding medication-taking for ADHD evolve as the child patient enters adulthood and moves towards autonomy and self-management. In all parts of this journey, decisions are shaped by a series of ‘trade-offs’, where potential benefits and harms of medication are weighed up.

Conclusions. This review offers a comprehensive insight into medication-taking experiences in ADHD. By considering the shifting locus of decision-making over time and the need for individuals and families to reconcile a variety of external influences, primary care and mental health clinicians can engage in holistic conversations with their patients to share decisions effectively.

Keywords: ADHD, medications, drugs, adherence.

Introduction

Attention Deficit hyperactivity disorder (ADHD) is characterized by the inability to sustain attention, modulate activity level and moderate impulsive actions (1). Although the resulting maladaptive behaviours are typically first recognized during childhood, symptoms often continue into adulthood (2). Untreated ADHD has been associated with significant social and psychological sequelae (3). Although pharmacotherapy is considered to be an effective treatment for ADHD (4), recommendations vary with regard to the use of medications as a first-line treatment (5,6).

Despite the apparent efficacy of medications and negative consequences of untreated ADHD, rates of adherence to medication...
regimes are low, with an estimated 50% of patients choosing to discontinue pharmacotherapy (7). ADHD is diagnosed based on clinical symptoms with a lack of objective physical examination or laboratory investigation findings, and moreover, ADHD behaviours can overlap and coexist with other mental health conditions (1). It has also received widespread and often contradictory media coverage in recent years (8). As such, there are likely to be a complex array of factors that contribute to treatment decisions.

Medication adherence is a multidimensional phenomenon that is shaped by factors relating to the patient, type of treatment, condition, healthcare system and individual social circumstances (9). Non-adherence is described as unintentional when the patient wants to adhere but is unable to due to lack of resources or capacity. Intentional adherence, meanwhile, occurs when individuals make an active choice not to comply with treatment recommendations (10). Research in the medical and social sciences has demonstrated the importance of social support in treatment adherence (11). In ADHD, a number of factors have been recognized, including general factors such as age and gender (12) and more specific factors such as duration of treatment and the presence of side effects (13).

Shared decision-making (SDM) is a well-established approach to improving the quality of health care (14,15) that involves clinicians providing information about treatment options and patients (or caregivers) providing information about values so that agreement on the best option for an individual patient can be reached (16). ADHD treatment guidelines recognize the importance of individual family values, concerns and preferences when deciding on treatment options (5,6), emphasizing that SDM is an essential component of ADHD care. Despite this, SDM during the treatment planning process for children newly diagnosed with ADHD has been shown to be limited (17). There is, therefore, a need to support clinicians to better share decisions with ADHD patients and their caregivers.

While a number of qualitative studies have explored patients’ and caregivers’ perspectives on ADHD medication, the clinical and policy application of their findings may be limited by the variety of study settings and populations and the relatively small individual study sample sizes. This review sought to synthesize the findings of these individual studies and was driven by the following question: ‘How can clinicians effectively share decisions about treatment for ADHD?’

Methods
Selection of studies for inclusion
We systematically searched five databases (MEDLINE, Embase, PsycINFO, SCOPUS and CINAHL) for relevant articles. These databases were chosen to maximize our ability to identify articles from both clinical and non-clinical journals. Search criteria comprised terms in three groups: methodology (search terms qualitative; focus group; interview; ethnography and thematic), focus (search terms medication; adherence; compliance; concordance and drug) and sample (search terms ADHD; ADD and attention deficit hyperactivity disorder,). These search terms were combined using Boolean logic terms (OR within the groups and AND between groups). The search was restricted to articles written in English and published in peer-reviewed journals. Searches were conducted in October 2015 and were restricted to articles published since 1987, as this was the first use of the terminology attention deficit/hyperactivity disorder, appearing in the revision of the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R) (18). It is well recognized that qualitative studies can be hard to identify, and that systematic reviews cannot rely on database searching alone (19). In light of this, we also manually searched bibliographies.

All identified titles and abstracts were screened by one researcher (SL). In addition, 10% were independently screened by a second researcher (MAR), with no discrepancies in selections. Studies that were excluded on the basis of abstracts alone typically did not use qualitative methodologies or did not focus on medication-taking experiences. Full-text articles were obtained for all selected abstracts and assessed for inclusion by two researchers (SL and MAR). Inclusion criteria were:

1. Focuses on individuals with ADHD
2. explores medication-taking experiences of patients and/or their caregivers
3. Uses a qualitative methodology
4. Original research paper published in English in a peer-reviewed journal

Critical appraisal
Articles selected for inclusion were independently appraised by two authors (SL and MAR) using the Critical Appraisal Skills Programme (CASP) qualitative research checklist (20), an established tool for the appraisal of qualitative studies. Only articles scoring >50% were included in the synthesis.

In light of the debate surrounding the value of critical appraisal in qualitative synthesizes, articles were additionally assessed with regard to their relevance to our research question, using the criteria set out by Dixon-Woods et al. (21). Articles included in our synthesis were classified as either ‘Key Papers’—where content closely mirrored the topic of our research question—or ‘Satisfactory Papers’—studies providing a smaller contribution to our synthesis. This classification was agreed upon by two researchers (SL and MAR) and is presented to allow readers to recognize the relative contribution of individual articles to the review

Synthesis
Included studies were synthesized using a meta-ethnographic approach. Meta-ethnography is an approach to the synthesis of qualitative studies pioneered by Noblit and Hare (22). It can be considered as similar to meta-analysis for quantitative research in that it aims to provide a comprehensive insight into the topic of research. However, meta-ethnography differs from meta-analysis in that it seeks to interpret the results of individual studies to create a new conceptual understanding of the subject. It has previously been used to synthesize findings about medication-taking experiences, including in mental illness (23).

Data were extracted from the included articles in the form of ‘first-order constructs’ and ‘second-order constructs’. First-order constructs are examples of direct quotations from research participants, while second-order constructs are the interpretations of these quotations offered by the original researchers. These definitions of first- and second-order constructs have been previously used in health research (24). For each second-order construct extracted from an article, one or more first-order constructs were collected to provide the reviewers with a clearer insight into the meanings. Tables of second-order constructs were collated, which were developed by the authors, into ‘third-order constructs’—higher level interpretations of the second-order constructs derived from the synthesis. Finally, these third-order constructs were developed into an explanatory model of the key themes.
Results
Systematic review
Our search identified a total of 1985 titles and abstracts for screening, of which 26 were identified via hand searching of the bibliographies of key papers, with the rest identified via database search. Full-text articles were obtained for 54 articles. After assessment, 31 articles were found to meet our inclusion criteria. Figure 1 illustrates the systematic review process using a flowchart based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidance. Table 1 details the 31 articles selected for inclusion in the synthesis, including their demographic data. The 31 studies selected for inclusion in our synthesis comprise studies of caregivers, paediatric patients and adult patients across seven different countries.

Critical appraisal
All assessed articles scored above 50% on the CASP rating, and none was, therefore, excluded on grounds of poor quality. On assigning relevance scores, 13 articles were assigned as key papers and the remaining 18 designated satisfactory. These results are detailed in Table 1 (key papers denoted KP, satisfactory articles denoted SAT). It was noted that some included articles were supported by pharmaceutical industry funding, and this has been presented in Table 1 to demonstrate the spread.

Data extraction and synthesis
In total, 31 second-order constructs emerged from the original articles. These are detailed in Table 2, along with the articles from which they arise. Once the second-order constructs had been established by the review team, these were discussed in meetings and mapped in a series of diagrams to develop third-order constructs that describe the major themes shaping patients’ and caregivers’ experiences with medication. These are presented here and, to more clearly describe our findings, have been used to categorize individual second-order constructs:

- Coming to terms with ADHD
- Anticipated concerns about medication
- Experiences of the effects of medication
- External influences
- The development of self-management

Coming to terms with ADHD
For many caregivers, the diagnosis of ADHD was difficult to accept. Many articles noted that the decision to start medication was preceded by an acceptance of ADHD as a biological problem. Caregivers’ decisions about pharmacotherapy were also shaped by their beliefs about medication. For patients, the process of coming to terms with ADHD was often reflected in how ADHD or medication...
Table 1. Characteristics of articles included in the meta-ethnography

<table>
<thead>
<tr>
<th>Number</th>
<th>Author, Year</th>
<th>Study population</th>
<th>Sample size</th>
<th>Age of ADHD patients</th>
<th>Recruitment setting</th>
<th>Country</th>
<th>Methods</th>
<th>Relevance</th>
<th>Pharmaceutical funding</th>
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<td>3 focus groups</td>
<td>Range 3–12 at diagnosis</td>
<td>Recruitment agency</td>
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<td>Focus groups</td>
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<td>Adolescents</td>
<td>14 interviews</td>
<td>Range 12.5–16.5</td>
<td>Private practice and acquaintances</td>
<td>Israel</td>
<td>Semi-structured interviews</td>
<td>KP</td>
<td>Not stated</td>
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<td>Brinkman et al., 2009</td>
<td>Parents</td>
<td>12 focus groups</td>
<td>Range 6–17</td>
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<td>USA</td>
<td>Focus groups</td>
<td>KP</td>
<td>Yes</td>
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<td>Brinkman et al., 2012</td>
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<td>7 focus groups</td>
<td>Mean 15.1</td>
<td>Community paediatric clinic</td>
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<td>Focus groups</td>
<td>KP</td>
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<td>Bull and Whelan, 2006</td>
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<td>Range 5–15</td>
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<td>Canada</td>
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<td>Charach et al., 2014</td>
<td>Parents</td>
<td>24 interviews</td>
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<td>Canada</td>
<td>Focus groups</td>
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<td>Focus groups</td>
<td>KP</td>
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<td>Range 6–11</td>
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<td>Semi-structured interviews</td>
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<td>Parents</td>
<td>28 interviews</td>
<td>Range 6–15</td>
<td>San Diego ADHD project</td>
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<td>SAT</td>
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<td>10 interviews</td>
<td>Range 6–16</td>
<td>Secondary care and ADHD advocacy group</td>
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<td>Semi-structured interviews</td>
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<td>Parents</td>
<td>10 interviews</td>
<td>Range 8–22</td>
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<td>Interviews</td>
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<td>17^{42}</td>
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<td>Parents and adolescents</td>
<td>35 interviews</td>
<td>Mean 11.5</td>
<td>Paediatric clinics</td>
<td>Australia</td>
<td>Interviews and semi-structured questionnaire</td>
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<td>18^{43}</td>
<td>Leslie et al., 2007</td>
<td>Parents</td>
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<td>Mean 9.5</td>
<td>Primary care</td>
<td>USA</td>
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<td>No</td>
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<td>19^{44}</td>
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<td>21^{46}</td>
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<td>Range 18–57</td>
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<td>Semi-structured interviews</td>
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Table 1. Continued

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<th>Number</th>
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<th>Recruitment setting</th>
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<th>Relevance</th>
<th>Pharmaceutical funding</th>
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<td>Interviews and ethnographic inquiry</td>
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<td>25</td>
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<td>Mean 11.9 Range 6–17</td>
<td>Online panel</td>
<td>8 European countries</td>
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<td>Parents</td>
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<td>Mean 9.5 Range 6–12</td>
<td>Secondary care clinic</td>
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<td>Interviews using a picture-based method</td>
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<td>Focus groups and one-one interviews</td>
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<td>Semi-structured interviews</td>
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<td>Parents and children</td>
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<td>Range 11–16</td>
<td>Local education authority</td>
<td>UK</td>
<td>Semi-structured interviews</td>
<td>SAT</td>
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<td>Youth aged 10–21</td>
<td>6 focus groups</td>
<td>Mean 14.3 Range 10–21</td>
<td>Schools</td>
<td>Canada</td>
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<td>31</td>
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<td>Mean 18.2 Range 13–24</td>
<td>Paediatric and child and adult mental health clinics</td>
<td>UK</td>
<td>In-depth interviews</td>
<td>SAT</td>
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Experiences of the effects of medication

External influences

Anticipated concerns about medication

Both patients and caregivers had concerns about the long-term impact of medication. One parent stated: ‘I don’t know how it’s going to affect him in the future’ and another said: ‘I’m worried about potential side effects such as suicide’ (37). Anticipated concerns also included short-term worries such as fears about potential side effects before commencing medication. Many of these anticipated concerns were grounded in any objective information from clinicians or scientific literature but came from informal sources such as friends or family or the media.
This model also illustrates some of the external influences on decisions about medication, and how these influences can change over time. Several included studies dealt with the initial decision to start medication to treat ADHD. This decision was most often taken by parents/caregivers and was often influenced by pressures from school staff and the opinion of family and friends. Parents were also influenced by the portrayal of both medication and ADHD in the media. In the adolescent phase, during which patients and caregivers balanced the influence of varying professional demands become more important. The relationship between patient, caregiver and healthcare professional plays a role at all stages.

The concept of ‘trade-offs’ and the explanatory model combine to give a conceptual picture of the changing experience of medication-taking in ADHD. ‘Trade-offs’ are largely internal experiences that remain fairly constant throughout the stages of the treatment journey, even if different constructs bore more or less influence at different times. Conversely, the model of evolving decision-making
represents some of the external pressures, which change more consistently as the patient matures. The model is not intended to be a summary of the third-order constructs identified in our synthesis; indeed it contains a combination of both second- and third-order constructs. The relationships between individual second- and third-order constructs are outlined in Table 2, which also identifies the included articles that support them. Rather, it is intended to provide a conceptual summary of the complex and evolving processes involved in making decisions about medication-taking for ADHD, as well as illustrating the elements that were consistently highlighted by participants in the included studies.

Discussion

Summary

This synthesis of qualitative studies of medication-taking in ADHD demonstrates that patients’ and caregivers’ experiences can be broadly described by five main themes: Coming to terms with ADHD, Anticipated concerns about medication, Experiences of the effects of medication, External influences and the development of self-management. In addition, the explanatory model described above illustrates that the experience of medication-taking transforms as the patient matures and the locus of decision-making shifts from caregivers to patients. The longitudinal nature of this illustration demonstrates that to support patients in decision-making, clinicians must tailor their interventions to the appropriate stage of their disease experience.

Strengths and limitations

One of the limitations of this work is that we chose to combine data from studies involving children, adolescents and adults. This may have prevented us from appreciating the subtleties of the different experiences of children and adults with ADHD. However, we have attempted to overcome this by producing a longitudinal explanatory model, allowing readers to appreciate that experiences can vary considerably with age. While the explanatory model described in this article depicts a medication-taking journey starting in childhood and continuing into adulthood, many key findings such as the role of trade-offs or the development of self-management could be relevant to patients with ADHD diagnosed and treated later in life. In addition, the majority of articles in this synthesis originated in the USA, which could limit the generalizability of the findings to countries with different state health models and where drugs are less likely to be marketed directly to the public (57). However, with evidence of increasing prescribing tendencies for ADHD in the UK (58), a thorough understanding by clinicians of patients’ and carers’ concerns surrounding medication-taking becomes imperative. The review team in this study included clinically trained researchers which strengthens the clinical focus to our investigation.

Implications for research and practice

This review demonstrates that decisions about initiating and persisting with medications for ADHD are highly complex and are affected by a variety of factors, both internal and external. These findings match the results of previous studies that have described the complexity of treatment decisions and the importance of social-, medical- and treatment-related factors (12,13,59). A previous review exploring non-adherence to pharmacological treatments also proposed a model to guide practitioners working with patients. It proposed three clinical actions: ensuring that patients have the right information, helping patients become motivated to commit to treatment and assisting patients to overcome practical barriers (60). These actions broadly fit with the model generated in this review, which contains additional, disease-specific information. The evolving nature of decision-making as patients move into adulthood and the importance of educational and social functioning are particularly important features of adherence in ADHD compared with the broader adherence literature.

Clinicians involved in ADHD management should be aware of the importance of these factors, and the fact that they evolve from predominantly parental concerns in childhood, to more autonomous decisions in adolescence and adulthood. It is particularly important for clinicians to recognize that these decisions often involve compromises. It is likely that for a given patient, there will factors that both encourage and discourage them towards a choice to take medications. In the case of ADHD, this may be especially relevant because of the variation in clinical guidelines internationally. By recognizing this uncertainty, clinicians can allow individuals to voice their unease and consider all available options. Similarly, the relationships between patients and their caregivers evolve with time of life, as do the external influences on the individual and family unit. Clinicians can acknowledge this shifting dynamic and recognize the autonomy of adolescent patients by including them more in treatment decisions. Furthermore, they can probe individuals and families about family, peer, school and employer factors according to the stage of development of the patient. By voicing the influencing factors and acknowledging them in discussions, patient–clinician discussions can focus on key areas that will help to shape treatment choices.
Future research in this area might further explore the emerging family issues including sibling and parent dynamics and the types of media portrayals that influence perceptions of ADHD and its treatment. Although a proportion of articles included in this study were funded by pharmaceutical industry funding, a more detailed analysis of the effect of this funding was beyond the scope of this review and might be investigated in further studies. In addition, a clinical tool to help support decision-making could also be developed and tested, using the findings from this review.

This synthesis conceptualizes the evolving experiences of using medications for ADHD. Consideration of these findings by clinicians may allow better engagement with both patients and caregivers to support shared decision-making.

Declaration
Funding: none.
Contributions: SL, NRL and MAR were involved in study design and analysis and interpretation of data. SL and MAR drafted the manuscript and NRL critically revised it for important intellectual content. All authors approved the final version.
Conflict of interest: NRL and MAR were supported by fellowships from the National Institute of Health Research.

References